

The perceptions of nurses regarding the communication and cognition of persons with mild Alzheimer's dementia, within the Tygerberg district of Cape Town

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Declaration

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Abstract

This South African study aimed to determine the perceptions of a group of nurses regarding the care of mild Alzheimer's dementia (AD), with specific reference to the communication and cognitive abilities of these patients. A convenience sample, comprising of nurses, caring for persons with mild AD, was recruited, within five homes for the elderly in the Tygerberg district, within the Cape Town area, Western Cape. A qualitative research approach was used within the phenomenological tradition. Semi-structured interviews were conducted with 12 nurses. The data collected from the interviews was analysed qualitatively, using thematic analysis, with the components of inductive analysis, latent themes and constructionist epistemology.

The findings of this study indicate that there are minimal funds available for the care of senior citizens, including persons with AD, in South Africa. Minimal funding for governmental homes for the elderly leads to a few nurses often being the only health care professionals employed at these homes. The findings of this study illustrate that the majority of these nurses never received formal training with regards to AD care. These nurses were aware of a range of behavioural changes persons with AD experience due to motor, perceptual, cognitive and communicative deterioration and personality changes. They discussed both, the benefits and the challenges that these behavioural changes created, as well as coping strategies helping them overcome these challenges. It became evident that whilst nurses were aiming to provide the best care to the persons with mild AD, their focus of care was mainly on the physical aspects of care. Even though the nursing staff, in these homes, is well positioned to provide intervention to persons with mild AD in terms of their communication and cognition, they seemed to have had limited to no exposure to such interventions. The findings of this study, highlight the need for the development, presentation and administration of cognitive and communicative training interventions, aimed at the specific needs of the nurses working in governmental homes in the Tygerberg district.

Key words: Communication, Cognition, Homes for the Elderly, Mild Alzheimer's Dementia, Nurses' Perceptions, South Africa

Opsomming

Hierdie Suid-Afrikaanse studie was gemik om die persepsies van 'n groep van verpleegsters met betrekking tot die behandeling van Alzheimer se demensie (AD), en spesifiek die kommunikasie en kognitiewe vermoëns van hierdie pasiënte, te bepaal. 'n Gerieflikheidsteekproef, uit verpleegsters verantwoordelik vir die versorging van persone met geringe AD, was in vyf tehuis vir bejaardes, in die Tygerberg distrik, in Kaapstad, Wes-Kaap, gewerf. 'n Kwalitatiewe navorsingsbenadering was binne die fenomenologiese tradisie gebruik. Semi-gestruktureerde onderhoude was gevoer. Die data is kwalitatief ontleed, met behulp van tematiese analise. Die komponente van induktiewe ontleding, latente temas en konstruksionistiese epistemologie was gebruik.

Die bevindinge van hierdie studie en vorige literatuur dui aan, dat daar minimale fondse beskikbaar is, in Suid-Afrika, vir die versorging van bejaardes, insluitend persone met AD. Minimale fondse vir staat tehuise vir bejaardes veroorsaak dat 'n paar verpleegsters dikwels die enigste gesondheidswerkers in die tehuise is. Die bevindinge van hierdie studie toon dat die meerderheid van die verpleegsters nooit formele opleiding oor AD versorging ontvang het nie. Verpleegsters was bewus van die veelvuldige gedragsveranderinge van persone met AD as gevolg van motoriese, perseptuele, kognitiewe en kommunikatiewe agteruitgang en persoonlikheidsveranderinge. Hierdie gedragsveranderinge was deur die verpleegpersoneel as beide, voordelig en terselfdertyd uitdagend geïnterpreteer. Verpleegsters het ook hanteringstrategieë genoem, wat hulle gehelp het om hierdie uitdagings te oorkom. Dit het duidelik geword dat terwyl verpleegsters graag die beste sorg wou gee aan persone met geringe AD, was hulle fokus hoofsaaklik op die fisiese versorging van hierdie pasiënte. Selfs al is die verpleegpersoneel in hierdie tehuise vir bejaardes goed geposisioneer om kommunikatiewe en kognitiewe stimulasie aan persone met geringe AD te bied, lyk dit asof hulle beperkte tot geen blootstelling aan sulke stimuleringsprogramme gehad het nie. Deur die bevindinge van hierdie studie, word dit duidelik dat die persepsies van die verpleegsters die ontwikkeling, aanbieding en administrasie van kognitiewe en kommunikatiewe opleidingsintervensies, gemik op die verpleegsters in publieke tehuise vir bejaardes in Tygerberg, ondersteun.

Sleutelwoorde: Kognisie, Kommunikasie, Geringe Alzheimer se demensie, Tehuise vir Bejaardes, Verpleegsters Persepsies, Suid Afrika

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Chapter 1: Introduction and Literature review

South Africa's population is aging more rapidly compared to the rest of Africa (Borochowitz, 2011). The 2005 population census illustrated that approximately 7.6% of the total population in South Africa was 60 years of age or older which increased to 8% in the 2011 census (Statistics South Africa, 2014). An increase in South Africa's aging population could yield to an increase in senior citizens affected by dementia. In 2010, a prevalence of 118,352 persons with dementia was estimated in South Africa (Wimo, Winblad, & Jönsson, 2010).

Previously, dementia was defined as a syndrome and/or condition which lead to a decline of functioning of the patient's memory and at least one other cognitive ability (American Psychiatric Association, 1994). Today, the DSM-5 defines dementia as a neurocognitive disorder marked by a "significant cognitive decline from a previous level of performance in one or more of the cognitive domains", with cognitive deficits not being attributable to other mental disorders (Alzheimer's Australia, 2015, p.2). The decline in functioning is significant and thus interferes with independent daily life activities and the patients' participation in society (American Psychiatric Association, 1994; Alzheimer's Australia, 2015). Different types of dementia have been identified, the most common being Alzheimer's dementia (AD) (Kalaria et al., 2008; Oren, Willerton, & Smalla, 2014), also called referred to as 'major neurocognitive disorder' (Alzheimer's Australia, 2015). AD eventually leads to communication limitations which are associated with a decline in cognitive abilities (Hopper et al., 2013).

Early initiation of interventions post AD diagnosis can improve patients' outcome in terms of their cognition and functional ability (Burgener, Yang, Gilbert, & Marsh-Yant, 2008; Manthorpe, Iliffe, & Eden, 2003). Assuming that an AD diagnosis is not delayed, it suggests that persons with AD be diagnosed during the mild stage of the condition. Early initiation of interventions suggests that persons with mild AD should receive treatment shortly after their AD diagnosis to improve or maintain their functioning. Patients' functional status can be improved by means of pharmacological treatment and behavioural exercises, including mental and physical exercises. An American randomised, repeated-measures study specified that mental exercises for persons with AD, consist of cognitive training interventions (Burgener et al., 2008). These cognitive interventions lead to improved cognitive functions, including enhanced memory storage, information retrieval, orientation and discourse ability (Burgener et

al., 2008). Other mental exercises, aimed at patients with AD, are specific to communication (Adams & Gardiner, 2005). These communicative interventions focus on facilitating factors which enhance communication and the management of inhibiting factors which reduce communicative success. Due to the cognitive and communicative deficits associated with AD, speech-language therapists (SLTs) have a clear role in the care of individuals with AD. However, according to Hopper (2003, p.345)

Rehabilitation for dementia is plagued by misconceptions. Personal and professional caregivers of people with dementia often do not see the purpose of supporting rehabilitation efforts, when they know that the person with dementia is only ‘going to get worse’ anyway.

Furthermore, the financial support from the South African government for the care of senior citizens is minimal. Senior citizens suffering from a condition like AD have limited access to adequate health care services as promised in the Constitution of South Africa, section 27(2) (Borochowitz, 2011). This would mean that in AD care facilities, such as homes for the elderly, nurses regularly assume the role of being the sole health care professionals caring for persons with mild AD. Thereby, they are required to adopt multi-faceted roles working in South African governmental homes for the elderly.

Given the potentially increasing number of persons with AD, the restrictive health care funding for the senior citizens in South Africa and the absence of other health care professionals in AD care facilities, the SLT’s role includes motivating for and designing nursing programmes focused on cognitive and communicative stimulation for persons presenting with mild AD. Research literature indicates that previous nursing interventions have been applied internationally, with direct or indirect focus on communicative and cognitive stimulation (Bourgeois, Dijkstra, Burgio, & Allen, 2004; Burgio et al., 2001; Engelman, Altus, Mosier, & Mathews, 2003; Palmer & Withee, 1996). However, these interventions might not be applicable in a country as culturally diverse as South Africa (Mavundla, Toth, & Mphelane, 2009).

The above-mentioned literature illustrates that cognitive and communicative interventions are successful in maintaining and improving the functioning of persons with mild AD, which provides reason for choosing persons with mild AD as individuals under discussion. Due to the difficulty behind the application of existing AD interventions, developed in countries other

than South Africa, the researcher aims at gaining context-specific data by the nurses related to the communication and cognition of persons with mild AD. Reason for including the nurses as study population instead of SLTs, when examining communication and cognition, is grounded in the reality of nurses regularly being the sole health-care professionals in homes for the elderly. This means that even though SLTs are usually responsible for conducting communicative and cognitive interventions, nurses could acquire these skills, thereby enabling them to assist persons with mild AD in an environment often burdened by limited resources and finances. However, to determine and develop communicative and cognitive stimulation programmes, suitable for the South African context, it is necessary to find out what the perceptions of the nursing staff are with regards to the cognition and communication of persons with mild AD.

Literature review

This literature review provides the reader with an overall background of AD as a condition, before discussing AD in the context of South African governmental homes for the elderly. It is important to note that throughout the literature review reference is made to the moderate and severe stages of AD. Even though the researcher did not intend to investigate these stages of the condition, various nurse participants continuously referred to them and thus the literature review was expanded, providing background information to most of the nurses' statements. The focus of this study, nevertheless, remains on the mild stage of AD and the perceptions of nurses with regards to the care and more specifically, the communication and cognition of persons with mild AD. For the purpose of this study perceptions were defined as nurses' knowledge, attitudes, awareness and needs specific to the care of persons with AD. Due to the broad definition of 'perceptions', it will be discussed throughout the literature review under various headings, which are to follow.

The literature review first describes the features of Alzheimer's disease and AD, with specific reference to the alterations of the brain's anatomy and physiology as well as the core symptoms of AD. The prevalence and health economics of AD are considered next, followed by AD care and its effect on caregivers, including nurses. The subsequent section focuses on the management of AD, more specifically the pharmacological treatment and behavioural interventions. The review is concluded by discussing the role of nurses in the homes for the elderly, their perceptions and knowledge related to AD and their self-confidence as carers, as well as the nurses' approaches to management following successful intervention programmes.

Features of Alzheimer's Disease and AD

Worldwide research is conducted around the phenomenon of Alzheimer's disease, including Alzheimer's dementia. Alzheimer's disease can be defined as a progressive, non-reversible and degenerative pathology, caused by neurobiological changes, as will be discussed below (Dubois et al., 2010). These neurobiological changes lead to the development of dementia, more specifically referred to as Alzheimer's dementia (AD). AD can be defined as "a progressive, fatal neurodegenerative condition characterized by deterioration in cognition and memory, progressive impairment in the ability to carry out activities of daily living, and a number of neuropsychiatric symptoms" (Jalbert, Daiello, & Lapane, 2008, p.15). As AD is a consequence of Alzheimer's disease, neither occur independently, thus this study will refer to both as AD hereafter, except in section discussing the alteration of the brain's anatomy and physiology specific to Alzheimer's disease. In literature, dementia and AD are often used interchangeably, with dementia being the umbrella term also referring to AD. Hence for the consistency and coherence of terminology, this study will refer to AD instead of dementia.

AD has been extensively researched. However, contradictory findings within literature are found and thus it remains a research area of interest to many. Up to date, it has been established that AD can be divided into three stages, relating to the functioning of the person with AD. Potocnik (2013) defined the three stages as mild, moderate and severe AD. The mild stage of AD, or otherwise known as the early stage AD, is predominantly marked by cognitive deterioration, with patients usually requiring little assistance completing activities of daily living. During the moderate stage of AD, patients require assistance completing most activities of daily living and within the severe stage of the condition they will lose their ability to accomplish any activities independently (Mayo Clinic, 2017). The duration of AD can be between 6 months and 20 years (Potocnik, 2013). Many researchers have identified 1) the effect that Alzheimer's disease has on the brain's anatomy and physiology, as well as 2) the core symptoms of AD. These will be discussed below.

1. The Alterations of the Brain's Anatomy and Physiology

Blaszczyk and Mathys (2007) as well as Potocnik (2013, p.141) found that Alzheimer's disease is marked with "amyloid plaques, neurofibrillary tangles, and synaptic and neuronal loss with subsequent brain atrophy". By means of magnetic resonance imaging and computed tomography scan, it became clear that the brain anatomy of persons with Alzheimer's disease

altered, with the “flattening of gyri, widening of sulci, atrophied medial temporal lobes and enlarged ventricles” (Potocnik, 2013, p.141). Atrophy of the hippocampus, with almost 25% loss of volume, coincides with the first mild symptoms of AD (Killiany et al., 1993 & Lehericy et al., 1994 as cited in Fox et al., 1996). Neurochemically Alzheimer’s disease is marked with deficits in neurotransmitters including serotonin, noradrenaline and acetylcholine (Potocnik, 2013). Serotonin assists regulating appetite, sleep, mood and sexual drive (Andrews, 2010). Noradrenaline (also called Norepinephrine) increases the blood pressure and constricts the blood vessels (Gulli & Finley, 2003). Acetylcholine dilates the blood vessels and reduces the heartbeat as well as the blood pressure (Gulli & Finley, 2003). Not only deficits in these neurotransmitters but also chromosome mutation, including chromosomes 21, 19, 14 and 1, heightens the likelihood of Alzheimer’s disease (Potocnik, 2013).

2. The Core Symptoms of AD

Multiple symptoms have been identified as being part of AD. However, it is of significance to clarify that certain symptoms appear within different stages of the condition. The first symptoms associated with AD include memory loss and loss of other cognitive functions (Lindau et al., 2000). These and later-onset symptoms can be divided into five main categories, namely 2.1) motor, 2.2) cognitive, 2.3) communicative, 2.4) perceptual and 2.5) emotional symptoms as well as personality changes, as evident below. Even though they can be divided into the given categories, they are all interrelated, collectively influencing the functioning of persons with AD, resulting in some overlap in the discussion of the various symptoms.

2.1) Motor symptoms. There are contradictory findings in the research literature, regarding the motor functioning of persons with mild AD. It is unclear if motor functions tend to deteriorate or remain comparable with those of the healthy senior control groups. Pettersson, Olsson and Wahlund’s (2005) research illustrates that deterioration of motor function is evident in persons with mild AD. These individuals present with slow movement and battle to perform dual-tasks, that demand simultaneous cognitive task completion whilst performing other motor activities, such as walking. Further, persons with severe AD might present with an alteration in mobility, being unable to walk or restricted to a wheelchair (Alzheimer’s Disease International, 2009). Additionally, the severe stage of AD might result in the patients’ inability to feed themselves, due to motor difficulties (Alzheimer’s Disease International, 2009). However, Eslinger and Damasio (1986) illustrate that patients affected by AD were able to learn new motor tasks. They discuss the probability of neural preservation of motor, visual and

kinaesthetic information, which grant the maintenance and development of motor functions. These contradictory research findings might be an indication that motor difficulties of persons with AD are rather a result of simultaneous cognitive tasks, that motor symptoms may be limited by the nature of the motor tasks and/or certain symptoms (i.e. motor symptoms) of AD, do not affect all patients.

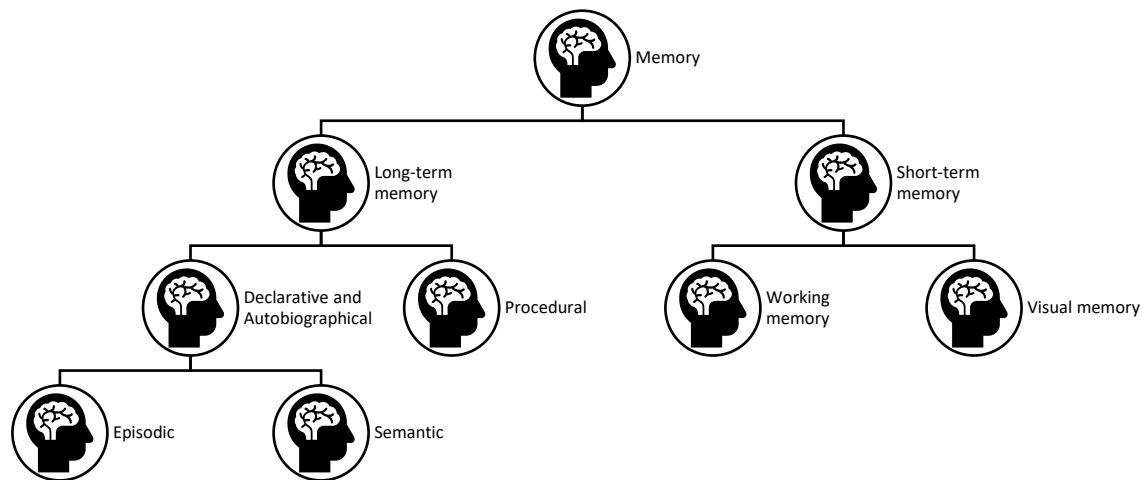
2.2) Cognitive symptoms. Cognitive symptoms include difficulties related to memory, cognitive flexibility, abstract thinking, executive functioning, reasoning and orientation. These symptoms are usually the early-onset symptoms of AD and deteriorate progressively during the course of the condition (Lindau et al., 2000). During the mild stage of AD, the most prevalent and evident cognitive dysfunction includes memory deficits. “Indeed, memory dysfunction is more frequently cited as the earliest clinical symptom in AD and is considered one of the primary diagnostic criteria” (Martin, Brouwers, Cox, & Fedio, 1985, p.323). However, caregivers, specifically family members, often disregard memory loss as being part of old-age, which leads to a delay of AD diagnosis (Werner, 2003). Whilst family members are regularly unaware of memory loss being a symptom of mild AD, 28% of these patients are aware of their limitations (Ostwald, Duggleby, & Hepburn, 2002). One patient, a former teacher, for example mentions

I quit teaching, basically, because I was having problems remembering and I didn’t keep up. I didn’t keep up my, uh . . . it was just a matter of remembering names at the particular time (Ostwald et al., 2002, p.306).

This would leave 72% of persons with AD unaware of their condition. Patients’ lack of understanding their condition is also referred to as anosognosia (Starkstein, Jorge, Mizrahi, & Robinson, 2006).

Anosognosia might be one of the results of changing memory functions in persons with AD. Different types of memory can be affected by AD, as evident by the figure below (Ally, 2012; Dijkstraa et al., 2004; Greeff, 2009; Haj, Antoine, Nandrino, & Kapogiannis, 2015; Hart, Kwentus, Harkins, & Taylor, 1988; Kawas et al., 2003; Squire & Zola, 1996; Zanetti et al., 2001).

Figure 1: Different types of memory:



Each type of memory will be discussed in the following paragraphs. The two memory types most commonly known by laypersons are short- and long-term memory. Short-term memory further consists of working and visual memory, whereas long-term memory comprises of declarative, autobiographical and procedural memory.

In the mild stages of the condition, short-term memory difficulties pose a challenge to learning novel information. Persons with mild AD present with variable memory performance and might at times forget information 10 minutes following the presentation thereof. Hart et al. (1988) provide an explanation for the potential speedy loss of novel information. They state that AD:

...is associated with a specific pattern of pathology in the subiculum and entorhinal cortex of the medial temporal lobe which effectively isolates the hippocampal formation from much of its input and output. Partial disconnection of the hippocampus from other brain regions might limit the amount of information effectively stored shortly after learning...Taken together, this data might suggest that a disruption in memory storage occurs shortly after learning in DAT (Dementia of the Alzheimer's type), but that remaining information can be sufficiently organised or assimilated to develop stable memory representations (Hart et al., 1988, p.35&36).

The working memory of persons with AD might also impact the functioning of their short-term memory. Working memory can be defined as processing previously stored or incoming information, by means of cognitive resources (Dijkstraa et al., 2004). Deficits in working memory of persons with AD result in difficulty to process previous events or everyday conversations. Difficulties to follow conversations can be explained in terms of limited memory capacity (Hart et al., 1988). Recalling information, necessary to comprehend a conversation, will exhaust memory capacity and will lead to patients forgetting other information provided during the conversation. Their difficulty to comprehend conversations is thus the result of their limited ability to follow entire conversations, due to memory capacity deficits. The strain on their memory capacity can be reduced by means of visual stimuli, increasing the amount and accuracy of information being recalled. Recall is then based on visual and verbal memory, making the use of memory capacity more efficient. Ally (2012) also describes enhanced recall, by means of verbal and visual cues, in terms of dual-coding, suggesting that a visual stimulus evokes an image and a verbal code. These two representations are stored in the memory of persons with AD. By providing a visual and verbal stimulus both representations are activated thus increasing the likelihood of successful recall.

The extent to which visual cues are truly helpful to a person with AD might also be determined by the patient's visual memory function. Visual memory refers to the identification and recall of object and spatial information (Wheeler & Treisman, 2002). Experiments show that about three to four objects are usually remembered by healthy individuals, with changes in the environment often remaining unrecognised. According to Kawas et al. (2003), poorer visual memory performance might be an early indication for an increased risk of AD. Hence, it becomes evident that persons with mild AD are very likely to present with visual memory deficits, thereby influencing the patients overall short-term memory function.

Long-term memory difficulties are a result of declarative, biographical and/or procedural memory deficits. According to different authors declarative memory comprises of semantic and episodic memory (Eichenbaum, 2000; Squire & Zola, 1996), whereas Haj et al. (2015) defined autobiographical memory in terms of semantic and episodic memory. For the purpose of this study, this discrepancy will be evaluated in terms of overlapping attributes that define declarative and autobiographical memory. Semantic memory comprises of overlearned vocabulary and general knowledge (Tulving, 1983 as cited in Dijkstraa et al., 2004). Semantic memory limitations, during the mild stage of the condition, results in difficulties to retrieve

words and facts during conversations, which lead to discourse difficulties, as will be discussed below. Episodic memory includes experiences of personal relevance (Haj et al., 2015). It seems to be evident that information of personal relevance, acquired earlier in life (e.g. childhood or early adulthood), becomes more strongly consolidated and integrated within the episodic memory, remaining more readily available during the mild stage of the condition (Haj et al., 2015). However, during the moderate or severe stages of the condition, patients might be at loss of strongly integrated personal information, resulting in patients' inability to recall personal past experiences or people, which can affect patients' ability to remember the names and faces of family members. Persons with severe AD tend to live in the past, thinking and dreaming about their past lives (Greeff, 2009). Maddox and Maddox (2006) termed this phenomenon a delusion. It can present itself as follows: the patient, affected by AD might talk about having visited people recently, who passed away years before.

As with the episodic memory, the procedural memory is preserved until the later stages of AD. The procedural memory permits individuals to use cognitive resources "of previous experiences without conscious recognition" (Zanetti et al., 2001, p. 264), e.g. the procedure behind making a tea. This allows for relatively normal memory function by persons with AD in situations where no conscious recollection of learned information is required. Of all the above-mentioned types of memory, the procedural memory is likely to be preserved the longest.

Another cognitive limitation, with which persons with AD are challenged, includes abstract thinking. Twenty percent of persons with mild AD have trouble thinking in various ways (Ostwald et al., 2002). This can be explained by their potential cognitive flexibility deficits. Cognitive flexibility provides individuals with the skill to adapt their behaviour and thinking to a changing context and thus assists with detecting novel information, using working memory, monitoring performance, evaluating and integrating options, inhibiting responses as well as making decisions (De Bartolo et al., 2009). This permits individuals to think about and analyse situations critically, thereby reasoning about all the available options. Difficulties related to cognitive flexibility can reduce patients' ability to think critically, analyse or evaluate certain situations and can present itself in various situations, as evident by the following examples. "Some...said they 'couldn't think'" (Ostwald et al., 2002, p.306). Persons with AD often also lose their interest in reading, watching television or listening to the radio (Greeff, 2009), potentially due to their lack of comprehension. Furthermore, they struggle to understand the core of a conversation, probably due to deficits with their working memory as discussed

above (MacDonald, Almor, Henderson, Kempler, & Andersen, 2001). Altogether, these above-mentioned difficulties are a sign of impaired cognitive flexibility, abstract thinking, executive functioning and reasoning skills. Patients presenting with these deficits and additional attention difficulties have a tendency for uninformed and sometimes detrimental decision-making (Langley et al., 1998). They might for example spend their funds inappropriately (Greeff, 2009). Such behaviour might be perceived as child-like by others, although it is a representation of deteriorating cognitive functions.

Persons with AD, furthermore, present with orientation limitations (Greeff, 2009). These patients struggle to orientate themselves to time, person, place and context. The lack of orientation in places can be the result of spatial memory deficits (MacDonald et al., 2001) or delirium (Maddox & Maddox, 2006), also known as an acute confusional state (Meagher, 2001). Patients might start wandering without a destination in mind, which can be detrimental to these patients, due to the increasing chances of them being lost and disorientated in various places (Maddox & Maddox, 2006). Further, even if these patients are found by others, they might not know who they are or where they need to be. Maddox and Maddox (2006) therefore urge that persons with AD, who experience orientation deficits, should be supervised at all times or that entrances and exits should be closed, so that they are unable to leave the premises without a caregiver.

2.3) Communicative symptoms. Communicative symptoms include an array of 2.3.1) language production difficulties, 2.3.2) language comprehension deficits and 2.3.3) speech motor alterations, as will be discussed below. The severity and features of language and speech problems can vary, depending on the degree of AD (Brookshire, 2007; Samuelsson & Hyde, 2011).

2.3.1) *Language production difficulties.* The language impairment resulting from AD is not distinctly defined, as it can vary depending on each individual person with AD. Nevertheless, it has been established that language impairments present itself on a semantic, pragmatic and syntactic level (Dijkstraa et al., 2004; Samuelsson & Hyde, 2011). First, the semantic and pragmatic language functions show deterioration, as they require more mental effort than syntactic language functions (Brookshire, 2007). The following paragraphs will describe the above-mentioned language limitations.

Semantic impairment presents itself initially, by means of word-finding problems (Samuelsson & Hyde, 2011). Word-finding problems can be defined as difficulties of persons with AD to retrieve adequate vocabulary from their memory (Dijkstraa et al., 2004). Within the severe stage of AD, semantic impairment comprises of the reduction of individuals' vocabulary, to the point, where patients are limited to producing echolalia, palilalia or merely vocalizations (Samuelsson & Hyde, 2011). The verbal output during the moderate and severe stage of AD can be described as stereotyped, vague, dysphasic and imprecise (Greeff, 2009). During the severe stages of AD, patients utilise more formulaic language, comprising of pause-fillers, idioms, conversational speech formulas, and other fixed expressions known to a home language speaker (Bridges & Van Lancker Sidtis, 2013). Examples of such utterances are 'hello' and 'It's nice to meet you'.

The pragmatic limitations during the mild stage of AD, involves difficulty in initiating and maintaining conversations (Ostwald et al., 2002). This includes difficulties in formulating cohesive, coherent and concise discourse structures (Dijkstraa et al., 2004). Cohesion is present when two elements in a discourse are related and dependent on each other for interpretation and comprehension thereof. Coherence is established when the speaker's utterances are closely related to the content and topic under discussion. Conciseness is achieved when additional information is added to the discourse, without reaching redundancy. Difficulties to produce cohesive, coherent and concise conversation will impact patients' ability to maintain a topic. This leads to persons with mild AD providing less or little information to the conversation, thus making it more challenging to engage in longer conversations with these patients (Carlomagno et al., 2005). Further, these patients struggle to choose a conversational topic. Most patients will also have difficulties answering a question like "How have things been going for you lately?", as it requires increased mental effort to answer open-ended question (Brookshire, 2007; Ostwald et al., 2002, p.306). The later stages of AD, are characterized by noise making and disruptive vocalizations at various times, not related to the conversational context (Samuelsson & Hyde, 2011). These vocalisations are often seen as disruptive behaviours. Furthermore, the severe stages are also regularly marked with "revisions, aborted phrases, empty phrases, repetitions, indefinite words and disruptive topic shifts" (Dijkstraa et al., 2004, p. 265).

Syntactic limitations, during the moderate and severe stage of AD, are marked by sentence fragmentation and deviations (Asp & de Villiers, 2010; Becker, 2004), as well as poor

comprehension (Vestal, Smith-Olinde, Hicks, Hutton, & Hart, 2006). Sentence fragmentation refers to syntactically incomplete sentences, whereas sentence deviation describes syntactic errors (Asp & de Villiers, 2010). Additionally, a decrease in the mean length of utterances becomes evident throughout the progression of AD until the patients are non-verbal or only use incomprehensible vocalisations (Samuelsson & Hyde, 2011).

2.3.2) *Language comprehension deficits.* During the mild stage of AD, deterioration of comprehension becomes evident and regresses consistently throughout the condition. The changes in comprehension might be directly related to changes in memory. As previously discussed, patients' inability to follow entire conversations, as a result of working memory inefficiencies, greatly affect their comprehension (Ally, 2012; Dijkstraa et al., 2004; Hart et al., 1988). Comprehension is further compromised by patients' cognitive flexibility deficits, resulting in their difficulty to think critically (Ostwald et al., 2002). Their thinking difficulty reduces their ability to comprehend figurative language (Brookshire, 2007).

Comprehension abilities also vary depending on the conversational topic and its personal relevance and experiences of persons with mild AD. Comprehension can be improved by topics of personal relevance, due to the strong integration of the information in patients' long-term memory (Haj et al., 2015). Comprehension difficulties within individual patients could also be explained by means of the capacity theory (Miyake et al., 1994 as cited in Dijkstraa et al., 2004, p. 265). This theory is based on the perception that:

... storage and computation functions in working memory compete with each other for limited cognitive resources under conditions of high demand on these resources. When the resource pool is about to be exceeded, a deallocation process occurs that limits processing and storage functions.

Consistent with the capacity theory, excessive information has been shown to result in the inability of persons with AD to store and process information adequately. Consequently, comprehension is improved by providing less information and repetitions, thereby permitting longer processing times (Dijkstraa et al., 2004), without burdening the working memory (Savundranayagam & Orange, 2014). Repetition and additional time might benefit the comprehension of persons with mild AD, but not necessarily patients during the moderate or severe stage of the condition.

2.3.3) *Speech motor alterations.* During the mild stage of AD, patients' speech abilities seem to be comparable with healthy senior citizens (Brookshire, 2007; Rousseaux, Sève, Vallet, Pasquier, & Mackowiak-Cordoliani, 2010; World Alzheimer's report, 2009). This means that the motor cortex, responsible for motor functions related to speech production, remains unaffected during the mild stage of the condition. Speech challenges only become evident as the condition progresses. It has been reported that persons with moderate to severe AD might present with slurred speech quality and reduced speech intensity (Brookshire, 2007; Rousseaux et al., 2010; World Alzheimer's report, 2009). Some might also display phonological errors during their speech production.

The above-mentioned communicative difficulties are deemed to be the result of cognitive limitations, particularly the working and semantic memory systems (Dijkstra et al., 2004; Samuelsson & Hyde, 2011). Further, the decline in executive functioning also confines the patients' language capabilities (Samuelsson & Hyde, 2011). The speech alterations, evident during the moderate to severe stages of the condition, seem to be the result of deterioration of the motor cortex responsible for speech production (Rousseaux et al., 2010).

2.4) *Perceptual symptoms.* Persons with mild AD often present with perceptual changes (Kavcic & Duffy, 2003; Lavenua & Pasquier, 2004; Maddox & Maddox, 2006; Rizzola, Andersona, Dawsonc, & Nawrotd, 2000) which include alterations in "spatial contrast sensitivity, colour, stereopsis, temporal resolution and motion" (Rizzola et al., 2000, p. 1157). These alterations manifest in difficulties with object identification and localization, route identification as well as reading difficulties. Persons with AD also present with a greater prevalence for spatial errors (Gasparinia et al., 2008). Furthermore, these patients tend to lose the ability to recognise emotions (Lavenua & Pasquier, 2004). Maddox and Maddox (2006) further specify that perceptual changes alter the perception of thirst and hunger of persons with AD. They thus have to be reminded to remain nourished and hydrated.

Some perceptual alterations are found to be caused by anatomical changes, responsible for visual deficits (Kavcic & Duffy, 2003; Rizzola et al., 2000). Visual discrepancies stem from the "degeneration of optic nerve fibers, arising from 'broad band' retinal ganglion cells" as well as "ventral and dorsal visual pathway deficits" (Rizzola et al., 2000, p.1164). Additionally, an association between cognitive decline and visual limitations has been found. It seems that

“visuospatial deficits have a distinctive regional distribution of cerebral metabolic impairment that is related to specific cognitive deficits” (Rizzola et al., 2000, p.1165).

2.5) Emotional symptoms and personality changes. AD can cause feelings of loss, which result in an array of negative emotions. Emotional responses prevalent in persons with mild AD include frustration and aggression regarding their lost abilities, as well as fear (Ostwald et al., 2002). Feelings of fear become particularly evident with regards to the Alzheimer’s condition, due to the unknown and unpredictable progression of the disease (Ostwald et al., 2002). The frustration and aggression experienced, by persons with mild AD, stem from patients’ inability to convey their needs (Maddox & Maddox, 2006). Interpreted in terms of the frustration-aggression hypothesis, patient’s aggression would be the result of their frustration (Berkowitz, 1989). Initially patients might present as more verbally aggressive but throughout the course of AD aggression becomes more physical. Overall aggression of persons with AD increases throughout the progression of the condition, potentially due to reduced cognitive functions resulting in less cognitive flexibility and limited problem-solving (Ostwald et al., 2002), regularly rendering aggression the only solution for persons with AD to eradicate disputes or convey their needs. Patients’ frustration is also aggravated by their limitations or inability in performing tasks, e.g. following conversations, adequately, which often aggravates feelings of loss.

AD is marked with patients’ losses of, for instance, driver’s licence, employment, ability to manage their environments (Ostwald et al., 2002) and other limitations, thus leading to an increasing loss of independence. The patients’ regression and overall loss of skills results in carers, including nurses, permitting limited to no independence during care activities, aggravating agitation in some persons with mild AD whilst reducing feelings of being overwhelmed in others (Sloane, Miller, Mitchel, Rader, & Swafford, 2007). Depending on the perceptions of patients, this lack of independence either facilitate or inhibit patient-nurse relationships, as patients either feel bothered or supported by nurses’ assistance. Throughout the condition, relationships are altered, due to the feelings of inadequacy, of patients not being able to meet others’ expectations, their difficulty in initiating or maintaining conversations and to reciprocate adequately. Often these feelings of inadequacy can lead to feelings of isolation, embarrassment and social withdrawal. These various feelings of loss can ultimately lead to persons with mild AD feeling as if they lost their own lives (Ostwald et al., 2002).

Relationships changes might also be the consequence of emotional changes in persons with mild AD. These include a decline of sensitivity, interest and affection (Greeff, 2009). Frequently these patients are seen as emotionally ‘shallow’ (Greeff, 2009, p.366). During the severe stage of the condition, persons with AD often lose their personality and become more “self-centred, hypochondrial, cantankerous and slovenly” (Greeff, 2009, p.366). Furthermore, 70% of persons with AD regularly present as agitated and aggressive or depressed (Cassimjee, Stuart, & Marchetti-Mercer, 2005). According to Cassimjee et al. (2005) these emotional changes can not only be attributed to the feelings of loss, as discussed by Ostwald et al. (2002), but may be related to the cognitive functioning of these patients. Increasingly, evidence seems to be showing a correlation between higher cognitive functions and depression, as well as lower cognitive functions and agitation (Cassimjee et al., 2005). Higher cognitive functioning is related to patients’ awareness of their deteriorating cognitive functioning, thus regularly resulting in depressive symptoms. Lower cognitive functioning is related to increased deterioration of the patient’s overall functioning, resulting in less independence of the patient, which tends to increase the patient’s level of frustration and agitation (Cassimjee et al., 2005). This research thus suggests that the level of agitation within an AD patient will rise, as the condition progresses and higher cognitive functioning is affected. According to Starr and Lonie (2007) disinhibition will also increase as the condition progresses. Therefore, if cognitive functioning can be improved or maintained by means of cognitive exercises, it would be beneficial, to expose patients to such stimulation. Thus, it might be possible to delay the alterations experienced by persons with AD, in terms of their emotions, emotional responses and their personalities.

Taking into account the mentioned symptoms, it becomes evident that throughout the course of AD symptoms in all five categories (motor, cognitive, communicative, perceptual and emotional) worsen. During the mild stage of AD, patients present as higher functioning with less symptoms. Patients’ quality of life would be preserved and enhanced if functioning could be maintained for longer periods of time. A SLT can be involved in assisting persons with mild AD to maintain their cognitive and communicative functioning, by means of stimulation, as will be discussed below. However, even though the above-mentioned symptoms and anatomical as well as physiological alterations are indicators of AD, symptoms vary across patients, making early diagnosis challenging.

A diagnosis should be made within a multi-disciplinary team, including the family or close friends of the patient (Greeff, 2009). The multi-disciplinary team should include physiotherapists, occupational therapists, general practitioners, psychiatrists, SLTs, social workers, neurologists, geriatricians and neuropsychologists (Fuller, 2015; Mayo Clinic, 2013). Different combinations of health care professionals have been suggested in different contexts. The family or close friends should also form an integral part of the team, as they are the experts regarding the patient's previous level of functioning. A comprehensive physical examination should be conducted to determine patients' neurological health, such as reflexes and muscle tone (Greeff, 2009; Mayo Clinic, 2015). A thorough history of symptoms, medication and drug abuse should also be obtained (Greeff, 2009). To exclude other medical conditions, potentially causing memory loss, such as thyroid disorders, blood tests can be executed. The mental and neuropsychological status of patients will also be examined, to determine patients' cognitive and communicative abilities (Mayo Clinic, 2015). Additional examinations which are favourable include magnetic resonance imaging, positive emission tomography or cerebrospinal fluid analysis (Greeff, 2009; Mayo Clinic, 2015). Administrations of these examinations enhance the chances of early Alzheimer's diagnosis and thus the potential for early interventions is exemplified. However, the availability and accessibility of such multidisciplinary services and equipment is limited in the South African public health care sector. For example, merely three magnetic resonance imaging scanners are available to the public sector in the Western Cape, South Africa (van Schouwenburg, Ackermann, & Pitcher, 2014). These scanners need to serve about 4.4 million people. Thus, the waiting period for a scan is increased. For instance, in Tygerberg hospital the waiting period for a scan can take up to 24 weeks or longer (van Schouwenburg et al., 2014). The limited accessibility and availability of such equipment and services might impact the early diagnosis of AD and might delay management of the above-mentioned symptoms. This is of concern especially because estimates show an increasing AD prevalence in South Africa, as will be discussed below, thereby increasing the demand for services and equipment.

Prevalence and Health Economics of AD

In 2014, Oren et al. (2014, p.247) estimated that worldwide there are more than 35 million individuals living with dementia, "and this prevalence rate is expected to double in the next 20 years". In 2015, the number of individuals living with dementia worldwide were reported to be 44 million, 60% of whom are living in lower and middle-income countries (De Jager, Joska, Hoffman, Borochowitz, & Combrinck, 2015). This percentage is expected to increase by 11%

by 2050. Contrary to previous research findings, Olayinka and Mbuyi (2014) found that in Africa the number of dementia patients is rising as well. They argue that previous African dementia prevalence studies were based on single communities, within an African country and not on African countries as whole. Furthermore, the contradictory findings might have been a result of insufficient diagnosis of AD in Africa. Milder forms of dementia might be underdiagnosed, due to low levels of awareness regarding dementia, as well as the shame involving the social and occupational limitations of the affected individual (De Jager et al., 2015). The shame can be linked to the cultural and social misconceptions associated with the AD, as will be discussed below. Moreover, underdiagnosis of AD might also be the result of health care professionals' deficient knowledge regarding the condition (De Jager et al., 2015). Health care professionals often tend to ascribe the symptoms to old-age. This could also indicate a need for clearer behavioural indicators of AD. Another factor influencing the diagnosis of AD in South Africa, could be related to the above-mentioned lack of access to and availability of medical services and equipment like magnetic resonance imaging scanners (van Schouwenburg et al., 2014).

Corresponding with the research by Olayinka and Mbuyi (2014), Borochowitz (2011) found that compared to the rest of the African continent, the number of South African senior citizens is rising more rapidly. In 2000, South Africa was regarded as having the second-highest number of senior citizens on the African continent (Borochowitz, 2011). As stated earlier, the 2005 population census illustrated that approximately 7.6% of the total population in South Africa was 60 years of age or older which increased to 8% in 2011 (Statistics South Africa, 2014). Additionally, De Jager et al. (2015) states that the South African population aged 60 years or older might rise to 11% by 2030 with a subsequent increase in the prevalence of AD. In 2010, a total of 118352 patients were living with dementia in South Africa (Wimo et al., 2010). Up to date, this number has probably increased, as the number of individuals aged 60 years and older also rose, over the past 5 years.

De Jager et al. (2015) questions South Africa's level of preparedness for the increasing number of persons with AD. In Africa, only nine countries have one or more national psychiatric association and only South Africa has "a section addressing psychiatry for the elderly in the national psychiatric association" (De Mendonça Lima, Leibing, & Buschfort, 2008, p.9). Moreover, in 2011, South Africa "had fewer than ten geriatricians and fewer than five specialists in old-age psychiatry for a population of 3.8 million persons aged above 60 years"

(De Jager et al., 2015). Most of South Africa's AD care and caregiver training is provided by non-governmental organisations, such as Alzheimer's South Africa. De Jager et al. (2015) report that 79% of patients that attended a memory clinic in Cape Town were taken care of by family members. Nevertheless, an estimated 300.000 individuals pass away yearly, in South Africa, due to the HIV and AIDS epidemic (Van der Poel & Pretorius, 2009). This epidemic could leave many senior citizens without families to take care of them. Alarming, merely 2% of senior citizens requiring 24-hour nursing care, are accommodated for (De Jager et al., 2015). The lack of such institutional care might lie in the expenses linked to the maintenance and attendance of these institutions (Ferri et al., 2005). Most of these South African institutions are financed by non-governmental organisations with minimal financial support from the government (Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012). The funds, provided by the government, cannot only be used for building these institutions but need to be distributed towards nursing salaries, building and maintenance costs of the homes for the elderly as well as patient care. It is therefore apparent that South Africa has limited homes for the elderly, making them less accessible for senior citizens and that existing homes have limited resources which influences the quality of care the senior citizens receive within these homes. Evidently, persons with AD have minimal access to their right to adequate housing, as outlined in the South African Constitution in section 26 (Borochowitz, 2011).

In high income countries (like Europe or America), there are multiple established homes for the elderly in which persons with AD can reside. These homes are run at great costs and therefore most lower and middle-income countries care for persons with AD within their communities (Wimo et al., 2013). This form of informal care often presents itself as unpaid help in lower and middle-income countries. However, even though informal care is offered by the primary caregivers, the direct costs of AD remain. Direct costs include the medical care, medication and clinic visits (Wimo et al., 2013). It is of interest that only 11% of global societal funds are directed to lower and middle-income countries, such as South Africa, even though they present as under-resourced with regards to AD care (Borochowitz, 2011), with the majority of dementia patients living in these countries (Wimo et al., 2013). In 2010, 118352 patients lived with dementia in South Africa, which would have cost 3955.4 US dollars

(approximately R52327, 5¹) yearly, for each patient, if patients were cared for in formal settings.

Closely linked to the discussion of limited funds, it was found that even in the private health care sector, merely a small percentage of persons with AD receive pharmacological treatment (Truter, 2010). Potential reasons for the lack of pharmacological treatment could include the expense linked to the medication, the inadequate proof of long-term effectiveness of these medications or an absence of prescription. Galantamine and donepezil (further discussed below under the heading ‘Pharmacological Treatment’) account for 75% of prescribed AD medication, with an average cost of R596.15 per item. On average patients receive 4.4 items per year. Even in the private health sector, not all medical aids fund the costs of AD medication (Truter, 2010). Thus, rendering the costs for AD medication unaffordable for multiple patients in the private as well as government health sector.

It is evident that AD is not a priority in the South African health care system. This is reflected in the minimal geriatric services budgets and mental health funds, from the national government departments, especially the Department of Health (Borochowitz, 2011). The shortage of budgets and funds can be evaluated as distributive injustice (Moodley, 2011) to persons with mild AD, who have contributed to society by means of employment and their social engagement for years and who might be able to maintain their functions and quality of life for longer periods of time, if they were to be given adequate management. According to the South African Constitution in section 27(1), every senior citizen has the right to access health care services. The government is thus not meeting their constitutional obligation towards senior citizens, with regards to health care services, as established in section 27, paragraph 2 (Borochowitz, 2011).

Kalaria et al. (2008, p.11) concluded that

understanding the burden and costs of dementia is crucial to guide future health care and socioeconomic policy. Policymakers need evidence to prioritise and plan appropriately for the rapidly growing numbers of older people with dementia.

¹ Calculated at an exchange rate of 1 US dollar to 13,2 Rand on the 14 March 2017 using the website: <http://www.x-rates.com/table/?from=USD&amount=1>

Further, constitutional obligations as discussed by Borochowitz (2011) should be carried through. However, not only the deteriorating symptoms of AD, the health demographics as well as the prevalence of the condition highlight the importance of AD care, but also the effect of the condition on multiple caregivers exemplifies the burden associated with AD, as will be discussed below.

AD Care and its Effect on Caregivers, including Nurses

A diagnosis involving AD has multiple implications for the patient, immediate family as well as other primary caregivers, such as nurses (Heyns, Venter, Esterhuyse, Bam, & Odendaal, 2003). Other health care professionals such as physiotherapists, occupational therapists, general practitioners, psychiatrists, SLTs and social workers only play a secondary role in the care of persons with AD (Mavundla et al., 2009).

Persons with AD will progressively be reliant on more assistance in daily activities. It was found that the staff, including nurses caring for persons with AD, is more likely to present with burnout, compared to the staff caring for healthy senior citizens (Heyns et al., 2003; Mobily et al., 1992). The burnout presents itself on different levels. On psychosomatic level, the symptoms include

exhaustion, headaches, sleeplessness, peptic ulcers and other gastrointestinal problems and skin manifestations. On an emotional level, irritability, temper tantrums, avoidance of obligations and unwarranted paranoiac behaviour occur, and socially, the sufferer withdraws from family and friends (Heyns et al., 2003, p.81).

Nurses presenting with a burnout are emotionally exhausted, limiting their ability to provide enriched care to persons with AD. They become more indifferent or psychologically detached from the patients, which in return limits their involvement with the patients (Mobily et al., 1992).

Families of persons with AD do not only bear the emotional strain of the condition, eventually leading to a burnout, they also deal with the financial burdens, cultural negative conceptualization and stigmatisation associated with the disease (Mavundla et al., 2009). The financial burden becomes more apparent in families plagued by unemployment, a reality for many South African families considering the unemployment rate of 36,3 % in March 2016 (Statistics South Africa, 2016), increasing their financial burden and needs when caring for persons with AD. Financial burden is also related to constant and continuous caretaking of the

person with AD, posing difficulties for family members to maintain employment. Unemployment regularly leads to inadequate financial resources for all family members, as families often have limited savings and are thus reliant on an additional income. The financial burden regularly forces South African families to institutionalise the person with AD, enabling them to resume their employment or at best reduce their financial needs, if an appropriate institution can be accessed. As these families are more reliant on income from employment, the institutionalised family member might seldomly be visited. This contrasts with families' experiences in England who regularly visit their family member with AD in the homes for the elderly (Garity, 2006). Consequently, their family life is disrupted by continuously visiting the person with AD and they are often unable to pursue their jobs due to the time spent at the home. In England, the institutionalisation might thus be seen as creating additional burden, whereas in South Africa it might be interpreted as releasing financial burdens.

Adding to the financial burden, South African family members of persons with AD are more likely to experience stigmatisation. A South African study found that mental illnesses, such as AD, are believed by the majority of rural citizens, as being stress related or due to character weakness (Hugo et al., 2003 as cited in Mavundla et al., 2009). Persons with AD can thus be perceived as responsible for their condition, resulting in marginalization of these individuals and their carers, including the nursing staff (Mavundla et al., 2009). Overall, AD caregivers, including nurses, often feel as if they have minimal resources to deal with the daily challenges accompanied by the condition (Potgieter & Heyns, 2006). The caregivers, including nurses, and patients frequently share the persistent feeling of being overwhelmed and a loss of control, which reduces the nurses' self-confidence, in terms of their adequacy to care for persons with AD (Potgieter & Heyns, 2006).

Another burden identified by the nurses is that they regularly present with inadequate knowledge and skill related to AD care (Bryans, Keady, Turner, Wilcock, Downs, & Iliffe, 2003; Hyer, Molinari, Kaplan, & Jone, 2010). These inadequacies also result in reduced self-confidence of nurses (Bryans et al., 2003). Nurses who receive adequate information regarding the condition, pharmacological interventions and other management options, are thus better equipped to care for the patients with greater self-confidence (Bryans et al., 2003; Hyer et al., 2010). The different types of managements available for AD care, and nursing interventions targeting specific managements, will be discussed below.

Management of AD

According to Hopper (2003), even health care professionals, including SLTs believe that there is no intervention they can offer to persons with AD. In a survey conducted in Canada, it was found that 44% of the SLTs believed that persons with AD would not benefit from speech and language intervention. The same survey established that most health care professionals found AD interventions to be unethical, as patients' abilities would deteriorate. Research has however, shown that individuals with AD can benefit from 1) pharmacological treatments (Duthey, 2013), as well as 2) behavioural interventions (Hopper, 2003).

1. Pharmacological Treatment

Pharmacological treatment of AD provides only short-term improvement for six to eighteen months (Duthey, 2013). The medication administered include cholinesterase inhibitors and memantine (Blaszczyk & Mathys, 2007; Duthey, 2013). This medication does not alter the AD condition, but assists the brain to compensate for the neuron losses.

Cholinesterase inhibitors (donepezil and rivastigine) obstruct the enzyme cholinesterase, which breaks down acetylcholine, a neurotransmitter. AD is linked to low levels of acetylcholine, hence inhibiting the destruction of this neurotransmitter, leads to a direct improvement of brain function. The improvement in cognitive functions merely lasts for the first two years following pharmacological treatment. Duthey (2013) therefore specified that donepezil and rivastigine are pharmacological treatment options for mild and moderate AD as recommended by the National Institute of Health and Clinical Excellence.

Another theory is that Alzheimer's disease is caused by neurotoxic mechanisms, which leads to the destruction of glutamatergic pyramidal neurons, whereas the glutamatergic receptors are preserved. Excessive stimulation of these receptors can cause the loss of neurons, which can result in AD. To reduce the stimulation of the receptors, memantine, a glutamatergic receptor blocker, can be administered effectively (Duthey, 2013).

Other treatments currently being researched with regards to Alzheimer's disease, include antioxidants, hormone therapy and other agents such as ginkgo biloba (Duthey, 2013). Research has shown that oxidative stress and the deposits of free radicals lead to neuronal destruction within Alzheimer's disease. It appears that vitamin E and selegiline delay neural destruction. In terms of hormone replacement therapy, it is suggested oestrogen has antioxidant

and anti-inflammatory characteristics. It has been proposed that interactions between estrogenic and acetylcholine could reduce the probability of patients developing Alzheimer's disease. Additionally, the plant extract, ginkgo biloba seems to have antioxidative and anti-inflammatory properties and could thus potentially be administered by the same means as the hormone therapy.

Pharmacological treatment could also address the severe depression as well as extensive insomnia, which are both symptoms associated with AD (Blaszczyk & Mathys, 2007). These medications can however have significant side-effects and should thus be administered with care. A German study found that 33.3% of persons with AD were regularly given medication to manage patients' behaviours, for the convenience of the nurses and other staff (Kuske et al., 2009). Medication should not be provided to patients merely to the convenience of the staff, but should be administered when it becomes a requirement for the patient (Blaszczyk & Mathys, 2007).

2. Behavioural Interventions

The effectiveness of multiple nonpharmacological therapies has been examined with regards to AD management (Hopper et al., 2013). Olazarán and colleagues (2010, as cited in Hopper et al., 2013) identified the following interventions, namely cognitive therapy, music therapy, physical exercise, and reminiscence therapy. Moreover, Adams and Gardiner (2005) discuss the benefit of communication intervention with persons affected by AD. Many health care professionals are involved in providing various the above-mentioned therapies, namely physiotherapists, occupational therapists, general practitioners, psychiatrists, SLTs and social workers (Fuller, 2015).

The focus of this study is on 2.1) cognitive and 2.2) communicative intervention. It is of significance to mention that any intervention involving persons with AD, should be organised around reducing patients' participation restrictions and activity limitations (International Classification of Functioning, Disability and Health, 2001).

2.1) Cognitive intervention. Cognitive interventions are designed to improve memory, orientation, reasoning, abstract thinking and executive functioning. Cognitive intervention can occur in various settings and formats (Niu, Tan, Guan, Zhang, & Wang, 2010). It should always be tailored according to the patient's needs, incorporating individualised goals and strategies

that will assist the patient in achieving their greatest abilities (Hopper et al., 2013). Cognitive intervention can result in significant cognitive enhancement (Manthorpe et al., 2003; Niu et al., 2010). Cognitive intervention is an umbrella term representative for multiple informal and formal interventions. Informal interventions include games and/or singing, stimulating cognitive functions such as cognitive flexibility, reasoning and problem-solving (Sitzer, Twamley, & Jeste, 2006). Formal interventions include tasks such as 2.1.1) ‘The Reality Orientation Task’, 2.1.2) ‘The Fluency Task’, 2.1.3) ‘The Overlapping Figure Task’, 2.1.4) ‘The Photo-Story Learning Task’ (Niu et al., 2010), 2.1.5) as well as ‘Spaced Retrieval Training’ (Lewis & Trzinski, 2006; Oren et al., 2014). These will be discussed below.

2.1.1) The Reality Orientation Task. ‘The Reality Orientation Task’ comprises of two distinct supplementary tasks, including verbal and behavioural orientation (Saddichha & Pandey, 2008). Verbal orientation includes patients’ spoken orientation with regards to person, place and time (Niu et al., 2010). Behavioural orientation comprises of patients’ ability to physically find their way in the environment, without getting lost. ‘Reality Orientation’ is utilised to re-orientate persons with mild AD by repetitively providing orientation to time, place, context and person (O’Connell et al., 2007). This can be performed by means of verbal or visual cues. Verbal cues involve the therapist or the caregiver requesting orientation information and thereafter providing the adequate information. Visual cues can be provided by means of calendars, diaries, white boards or other visual material, assisting patients in orientating themselves within their environment (O’Connell et al., 2007). This task has been shown to reduce the speed in which cognitive decline occurs (Niu et al., 2010; Saddichha & Pandey, 2008). Patients exposed to these tasks, maintained their cognitive abilities, for up to 3 months’ post intervention. However, currently it is questionable how this task improves the patients’ overall well-being, communication and functional performance (Saddichha & Pandey, 2008).

2.1.2) The Fluency Task. ‘The Fluency Task’ comprises of verbal and category fluency (Niu et al., 2010). The verbal fluency task requests persons with mild AD to list multiple words, starting with a certain sound or syllable. Category fluency requires the patients to name as many words that fall within a specific semantic category (Niu et al., 2010), like clothes. The verbal and category fluency tasks are each to be completed within a 1 minute interval. If patients are unable to name words spontaneously, it is suggested that pictures, symbolising the target words, be presented to the patients, which they are then required to name. Arkin, Rose,

and Hopper (2000; as cited in Hopper, 2003) found that after pictorial exposure to ‘things people wear’, AD patients were able to name multiple items within a category naming task, whilst prior to the pictorial exposure, they could merely name a few. This improvement of patients’ responses can be seen as the result of priming. Priming is when a later response is based on a preceding associated stimulus (Hopper, 2003). These tasks are cognitively stimulating, as they “require cognitive flexibility in organizing and selecting lexical information, generation of a search strategy and the ability to switch from one category to another while inhibiting the preceding category (Niu et al., 2010, p.1105)”.

2.1.3) The Overlapping Figure Task. ‘The Overlapping Figure Task’ requires patients to recognise and name as many letters, numbers, objects and animals from multiple overlapping black and white figures (Niu et al., 2010). The goal being to recognise, select and name figures from a background; thereby expanding cognitive flexibility in identifying various overlapping figures, whilst inhibiting other symbols. Another exercise, which has shown to increase cognitive flexibility, was proposed by Arkin (2007) and involves the ‘Bingo Game’. The patient is requested to identify certain figures, as fast as possible, within a picture grid containing multiple different figures.

2.1.4) The Photo-Story Learning Task. Niu et al. (2010) utilise an array of photos to elicit short stories from persons with mild AD. The patients are exposed to the photos and are simultaneously asked several concrete and abstract questions, related to these pictures. This task aims at encoding and retrieving the episodic memory, affected by AD. Furthermore, storytelling, as elicited by this task, requires organisation of thoughts and summarizing elements of a story, which involves executive functioning. This task is found to be effective in retrieving the episodic memory (Niu et al., 2010).

2.1.5) Spaced Retrieval Training. Spaced retrieval training commences with the presentation of explicit information, such as words, chosen for recall (Lewis & Trzinski, 2006). Following the presentation of the target information, the patient is directly requested to repeat the information. Correct recollection is rewarded, usually with verbal praise, whereas incorrect responses are followed by the therapist providing the appropriate information again and retesting the patient immediately after. The task is repeated until the patient is able to answer the question correctly (Lewis & Trzinski, 2006). This intervention appears to benefit multiple memory deficits, including prospective memory (e.g. remembering doctors’ appointments),

procedural memory (e.g. remembering how to lift oneself out of bed), semantic memory (e.g. remembering names of objects) and recent episodic memory [e.g. remembering novel personal events (Oren et al., 2014)].

Following the descriptions of the above-mentioned interventions, it is evident that these target memory, cognitive flexibility, abstract thinking, reasoning and orientation. All of these interventions also result in verbal output, thus also stimulating language production and comprehension. Interventions specific to patients' language functions will be discussed below.

2.2) Communicative intervention. Dijkstra et al. (2004, p.277) describe that communicative intervention aims to improve the quality of life of persons with mild AD. If nursing home staff and family members of residents with AD can learn relatively easy techniques to enhance this conversation, the rewards of a communicative interaction without breakdowns will apply to both parties involved.

Multiple researchers investigated means of improving communication in persons with AD (Adams & Gardiner, 2005; Arkin, 2007; Brodaty & Griffin, 1984; Maddox & Maddox, 2006; Saddichha & Pandey, 2008). The following paragraphs will discuss communicative intervention focused on 2.2.1) language stimulation, 2.2.2) factors that will facilitate or inhibit communication as well as 2.2.3) the communicative benefits resulting from social activities.

2.2.1) Language stimulation. Language stimulation includes the utilisation of language enriching exercises, as proposed by Arkin (2007). This includes discourse prompts, such as picture descriptions (e.g. What is happening on this picture?) or prompted questions related to the pictures (e.g. What is the girl feeling? Why would you say that?). An additional discourse prompt is story recall. This technique involves the therapist reading a short story, posing a few questions regarding the narrative and then having the patient retell the story.

Object descriptions are also a means of eliciting discourse. Other discourse prompts include word association tasks, discussion of the similarities of objects or opinion and advice questions. Word association tasks include the recall of any thoughts or memories involving a specific word (e.g. birthday). Discussions regarding the similarities of objects (e.g. What do a cat and dog have in common?), as well as opinion and advice questions require cognitive functions,

such as reasoning and executive functioning (Arkin, 2007). One example of an opinion question could be requesting, if children should have iPads.

Other language enriching exercises include the completion of proverbs or sentences (Arkin, 2007). These completion tasks involve the therapist reading the initial part of the proverb or sentences, which the patient is required to complete. If the patient is unable to complete the proverb or the sentence, the therapist will complete the proverb or sentence for the patient. The person with mild AD is then asked to explain the meaning of the proverb or sentence (Arkin, 2007).

Arkin's study provides a strong level of evidence in terms of the efficacy of communication intervention (Arkin, 2007). Arkin's (2007) controlled clinical study showed that persons with AD receiving treatment had improved language and cognitive skills compared to the untreated AD control group. These interventions might have been successful as patients were challenged to produce an extensive amount of verbal output. These tasks aimed at the stimulation and elicitation of patients' language comprehension and production. Furthermore, most of the above-mentioned language tasks also involved utilizing cognitive skills, such as executive functioning and memory, which benefited patients' overall communicative and cognitive functioning. Patients' communicative functioning can further be improved by increasing the facilitative factors and reducing inhibiting factors which can affect conversations, as evident in the following section.

2.2.2) *Factors that facilitate or inhibit communication.* Research has highlighted certain factors that can facilitate or inhibit the communication of persons with AD. Therapists' or caregivers' consideration of these factors can alter their communication with the patient. Addressing these factors can serve as therapy techniques and communication guidelines (Adams & Gardiner, 2005). By increasing the facilitating and decreasing the inhibiting factors, therapists and caregivers can provide patients with support during their communication (Adams & Gardiner, 2005). Improved communication with persons with AD is desirable as it can maintain or enhance patients' cognitive and communicative abilities, thus leading to an overall enriched life (Adams & Gardiner, 2005; Arkin, 2007; Burgener et al., 2008). The facilitating and inhibiting factors comprise of environmental and conversational cues, relevant to all stages of persons with AD. Persons with mild AD will be able to react more spontaneously and independently to some cues, whereas persons with moderate or severe AD will require

additional assistance. Facilitating environmental factors include the removal of unwanted stimuli, persons with AD assuming the right spatial position, as well as the inclusion of pictures, photos or objects in conversations (Adams & Gardiner, 2005; Maddox & Maddox, 2006; Saddichha & Pandey, 2008). Facilitating conversational aspects include the promotion of equal participation during conversations, respecting and valuing conversational contributions, sensitivity to non-verbal cues, promotion of joint decision making and the conversational partner's adjustment of verbal output (Adams & Gardiner, 2005; Brodaty & Griffin, 1984; Maddox & Maddox, 2006; Saddichha & Pandey, 2008). The various facilitating factors will be discussed below.

Removal of unwanted stimuli. Persons with AD are regularly and easily distracted or overstimulated (Adams & Gardiner, 2005; Maddox & Maddox, 2006). Thus, leading to the suggestion that stimuli impeding the conversation should ideally be removed or reduced (Adams & Gardiner, 2005). Impeding stimuli can be defined as all stimuli of auditory, visual or tactile nature, not being of value to or diverting from the conversational content. For example, if the television were to impede the conversation, it would be suggested to switch off the television while communicating, thereby removing the unwanted stimuli (Maddox & Maddox, 2006). If the television were to remain switched on, the patient might focus on the visual and auditory stimuli provided by the television and ignore the conversational partner. Within the given scenario, a conversation could merely be successful if the television were to be switched off.

Persons with AD assuming the right spatial position. Persons with AD should face their conversational partner and away from distracting stimuli, like a window (Adams & Gardiner, 2005). It is also suggested that in group settings the distance between all conversational partners should be equal and in close proximity (Adams & Gardiner, 2005), thereby increasing the conversational and social closeness between all conversational participants.

Inclusion of pictures, photos or objects in conversations. During the mild stage of AD this strategy can be used to promote elaborate conversations. A photo of patient's holiday adventures can be used to remind him or her of the adventures and promote conversation thereof. Furthermore, the cognitive load and the strain on patients' working memory during a conversation can be reduced by including pictures or objects relevant to the topic being discussed. This becomes more vital throughout patients' progression of AD and their

consequent cognitive deterioration, increasingly resulting in more difficulty for patients to follow a conversation (Saddichha & Pandey, 2008). During severe stages of the condition, Maddox and Maddox (2006) provided an example and suggested that during mealtimes, food should be brought to the patients, providing them with a choice as to what they want to eat.

Promotion of equal participation during conversations. Ideally each conversational participant should receive equal opportunities to talk. This means that conversational partners of persons with AD should encourage patients to take their conversational turn (Adams & Gardiner, 2005). Conversational turns can be elicited by prompted questions, as discussed previously, within the language stimulation section. Promoting conversational turns result in greater verbal output, which can lead to improved language production and cognitive functioning by persons with AD (Arkin, 2007).

Respecting and valuing conversational contributions. It is however, not sufficient to merely promote conversational participation. Adams and Gardiner (2005) discuss the significance of respecting and valuing conversational contributions. Thus, even when patients appear to be confused, it is important that their contributions are acknowledged and not disregarded, as this might result in the patient's refusal to communicate (Adams & Gardiner, 2005). By acknowledging and responding to patients' contributions a 'verbal positive affect' is established (Levy-Storms, 2008). This means that a positive conversational and social agreement is formed, thereby facilitating communication and enhancing the probability of communicative success.

Sensitivity to non-verbal cues. Conversational partners of persons with AD should pay attention to the patient's bodily movements, facial expression and moods. These non-verbal cues could provide an additional indication of the patient's conversational content (Adams & Gardiner, 2005). The conversational partner should not only take the patient's non-verbal cues into account, but also focus on their own body language and moods (Maddox & Maddox, 2006; Magai, Cohen, & Gomberg, 2002). The body language and moods of the conversational partner can inhibit or facilitate communication. For example, it has become evident that nurses, who are in a good mood, might impact patients' moods positively, thereby simultaneously increasing patients' participation in activities and conversations (Magai et al., 2002).

Promotion of joint decision making. It is suggested that the person with AD be included, as far as possible, in decision making, regarding daily activities (Adams & Gardiner, 2005).

Joint decision making seems to promote communication (Adams & Gardiner, 2005). By means of joint decision making, patients are asked to provide their opinions, thereby promoting verbal output and the patients' autonomy (Moodley, 2011). Autonomy refers to patients' right and ability to take part in decisions about their lives, following the provision of all essential information as well as the understanding thereof (Moodley, 2011). Increasing patients' autonomy can improve patients' quality of life, as it provides them with a sense of responsibility, thus reducing the feelings of inadequacy as previously discussed (Ostwald et al., 2002).

The conversational partner's adjustment of verbal output. Due to the increasing cognitive and communicative limitations of persons with AD, it is suggested that the conversational partners should adjust their verbal output, by simplifying and keeping it concrete, to aid comprehension (Brodaty & Griffin, 1984; Maddox & Maddox, 2006). Verbal output could be simplified by eliminating embedded clauses, thereby reducing the mean length utterance and providing merely one idea per sentence (Savundranayagam & Orange, 2014). Sentence presentation should be slow and clear (Maddox & Maddox, 2006). To the contrary, Savundranayagam and Orange (2014) discuss slow presentation of information as an ineffective communication strategy, burdening patients' working memory, as the retention of a whole utterance would take longer. The slow presentation of short utterances will reduce the burden on the working memory, as will repetition and emphasis of vital information. Additionally, it is always significant to acknowledge persons with mild AD as equal conversational partners and not as inferior conversationalists, even if they present with communicative deficits (Brodaty & Griffin, 1984). The conversational partner should also never raise their voice throughout conversations, speak in a "gentle tone of voice" and should remain calm (Maddox & Maddox, 2006, p. 60), thereby promoting conversational participation by persons with mild AD. Eye contact should be maintained throughout the conversation with persons with AD (Maddox & Maddox, 2006).

Considering all of the above, it becomes evident that there are many factors that can facilitate communication. Nevertheless, research also shows that environmental and conversational factors can inhibit communication. An inhibiting environmental factor is to change a routine or environment, whereas the inhibiting conversational factors include interrupting or ridiculing the patient, speaking on the patient's behalf, talking out of earshot and taking sides. These inhibiting factors will be discussed below.

Changing a routine or environment. According to Maddox and Maddox (2006), a change in routine and environment can negatively impact communication. Persons with AD thrive within routines (Maddox & Maddox, 2006) and an alteration thereof can result in disorientation, confusion and reduced communication.

Interrupting or ridiculing the patient. Persons with AD are regularly interrupted by conversational partners (Adams & Gardiner, 2005). Reasons for these interruptions may include deficits within the patient's content of speech or impatience with the patients, as additional time might be required for them to formulate their thoughts. Nevertheless, persons with AD should not be ridiculed, even if their verbal output deviates from the 'truth'. It should be understood as a change in perception and not as an intention to lie. Patients should never be viewed or treated as foolish or silly (Adams & Gardiner, 2005).

Speaking on the patient's behalf. Conversational partners might tend to speak on behalf of the person with AD (Adams & Gardiner, 2005). This behaviour could be related to the fact that conversational partners, usually caregivers, assume that they know what is best for the patient. This assumption can result in conversational partners reinterpreting what the patient has said, thereby potentially ignoring the real needs and feelings of the patient. This should be avoided, as it may constrain the communication intent of the patient (Adams & Gardiner, 2005) and reduce the patient's autonomy (Moodley, 2011).

Talking out of earshot. Patients should not be discussed, as if they are not present in the room (Maddox & Maddox, 2006). Conversational partners might feel that persons with AD are not competent enough to communicate or make a decision. They might be likely to assume the dominant role in their relationships with the patients, speaking about the patients and making decisions on their behalf. Discussions involving the patients might occur facing them or in the absence of the patients. At times, the patients might be in the room, able to see the other conversational partners discussing them and yet too far to be able to follow what their discussion is about. Patients might assume a 'special' relationship between the other conversational partners on grounds of their private informational exchange. Patients might feel excluded or as if they are spoken about, potentially increasing their feelings of insecurity and thus removing themselves completely from the conversational context (Adams & Gardiner, 2005).

Taking sides. Taking sides occurs when decisions, for or against something, need to be made. All individuals in agreement in terms of their decision, form a side. This side automatically opposes the decision of the others. It becomes particularly difficult, in cases of disagreement between the therapist and the person with mild AD, if caregivers choose the side of the therapist, thereby building an opposition against the patient (Adams & Gardiner, 2005). This can also result in patients' withdrawing from the conversational context and will thus, make joint decision making, as previously proposed, challenging. Overall, this may lead to future communication difficulties between all conversational partners and the person with AD (Adams & Gardiner, 2005). Instead patients should be given the opportunity to explain their views. By considering the patients' views and incorporating additional suggestions, patients form part of the decision-making process thereby facilitating communication between patients and all conversational partners.

The above-mentioned communicative interventions for persons with AD include language stimulation, as well as efforts to increase the communication facilitating factors and to decrease the communication inhibiting factors. These communicative interventions can be incorporated into social activities, which could lead to overall communicative benefits and improved quality of life, as will be discussed below.

2.2.3) *The communicative benefits resulting from social activities.* According to Arkin (2007), persons with mild AD, involved in volunteering and recreational activities will benefit from the regular mental and physical stimulation obtained by such activities. These activities can include care involving children, animals or nursing home residents, as well as packing community food bags or stamping books at libraries. All the stated activities, especially the care undertakings, will involve cognitive and communicative stimulation and elicitation, to a certain extent. According to Arkin (2007) emotional and physical benefits are ensured through these activities and if cognitive decline could be slowed by means of volunteering, this would be another advantage.

Considering all the above-mentioned cognitive and communicative interventions, as well as the different strategies, it becomes evident that intervention can benefit the overall functioning of persons with AD. These interventions have shown improvements of patients' memory storage and retrieval, orientation as well as discourse abilities (Burgener et al., 2008).

Furthermore, persons with AD can present with enhanced engagement in their environment, when exposed to cognitive and communicative stimulation (Hopper, 2003). Moreover, cognitive stimulation, targeting memory, cognitive flexibility, abstract thinking and reasoning, can improve patients' emotions and personality disorders (Niu et al., 2010). It is suggested that the depression and apathy of persons with AD, is related to the "hypoperfusion of the anterior cingulate gyrus and dorsolateral prefrontal regions" and the "hypometabolism in the orbitofrontal regions" (Niu et al., 2010, p.1108). The specified brain areas are located in the frontal lobe and are stimulated during cognitive and communicative tasks. Thus, by providing cognitive interventions, blood flow within the frontal lobe is increased, which can result in reducing apathy and depressive symptoms (Niu et al., 2010).

Intervention research has indicated that intervention can benefit persons with AD in terms of their communication, cognitive and physical activities as well as their emotional functioning. Burgener et al. (2008) suggested that the best outcome, with regards to the AD care, is obtained by combining pharmacological as well as nonpharmacological interventions (i.e. cognitive, communicative and physical therapy). Furthermore, it seems that different types of nonpharmacological interventions benefit each other, by targeting sets of different skills, eventually combined to form holistic interlinked capabilities. For example, evidence is growing that physical exercise, by means of motor learning can improve cognitive functioning. In conclusion, Burgener et al. (2008) found that combinations of various therapies, during the mild stage of AD, improved patients' functional abilities and participation in daily activities. This finding should provide enough motivation for AD intervention programmes to take place in homes for the elderly, throughout South Africa, best provided by nurses, as will become apparent in the following sections.

Who Could Best Provide AD Intervention? The Position of Nurses in Homes for the Elderly

AD is not of a priority to the South African health care system (Borochowitz, 2011). Considering the minimal resources available for AD care, focus within homes for the elderly should be placed on effective nursing training, with regards to the management of AD. It would be unrealistic to suggest extensive therapy, involving an array of health care professionals, as this will increase the financial burden experienced by family members of persons with AD (Borochowitz, 2011; Gurayah, 2015) and may exceed what the public health sector can reasonably afford. Also accounting for the general shortage of health care professionals in the

South African public health care sector (Labonté et al., 2015), it becomes evident that the employment of numerous health care professionals in governmental homes for the elderly is and will remain utopian. Traditional Africans often experience the care by health care professionals or caregivers, other than their own families, as foreign.

Within the African culture there seems to be an implicit perception that younger individuals take care of their parents, as personified in the notion of Ubuntu (Gurayah, 2015). This concept around collectivity specifies that all individuals are part of their community and are thus required to fulfil their commitments to the collective. Nevertheless, caring for a person with AD can be straining and a financial burden, especially because family members often fail to maintain their employment or are unable to financially support the patient due to their own unemployment. Thus, if homes for the elderly allow for placements, some families prefer or require placing these patients in the homes, to resume their employment and reduce their financial burden (Mavundla et al., 2009). Nurses and carers working in the homes for the elderly would then provide services to these patients, who require 24-hour care (Department of Social Development, 2016). However, as stated earlier, merely 2% of senior citizens requiring 24-hour nursing care, are accommodated for (De Jager et al., 2015). Thus, even though senior citizens might be adequate candidates for the homes, as established by the Department of Social Development (2016), they might not have access to such an institution.

Candidates for homes are those individuals too frail and in need of 24-hour services, individuals receiving an old-age grant as well as females older than 60 years and males older than 65 (Department of Social Development, 2016). Most homes are designed to cater for the senior citizens' basic needs and leisure time (Liebig, 2003). The majority of homes for the elderly have a communal dining area, a television room and resident rooms. Senior citizens are provided with meals and receive support with their activities of daily living (Liebig, 2003). Nurses are responsible for assisting senior citizens with their daily activities (Perold & Muller, 2000), always requiring patience and respect towards them (World Alzheimer Report, 2009).

According to the South African Nursing Council (2005, p.1), the Nursing Act 50, describes the obligations of the nurses as follows; nursing is

...a caring profession which enables and supports the patient, ill or well, at all stages of life, to achieve and maintain health or where this is not possible, cares for the patient so that he lives in dignity until death.

The South African Nursing Council differentiates between four different types of nurses, namely a registered nurse, enrolled nurse, enrolled auxiliary nurse and student auxiliary nurse (Perold & Muller, 2000). The scope of practice of the nurses depends on their level of training (Perold, 2003). A registered nurse has to complete four years of training at a university or should have a diploma (Perold & Muller, 2000). An enrolled nurse has to complete two years of training at a hospital and nursing college. An enrolled auxiliary nurse has to complete 44 weeks of training at a home for the elderly or a hospital registered as a training institute with the South African Nursing Council. A student auxiliary nurse is in the training process with a training institute registered with the South African Nursing Council (Perold & Muller, 2000). The scope of practise of an enrolled auxiliary nurse would, for example, entail the following (South African Nursing Council, 2005, para.6):

- (a) The promotion and maintenance of the health of a patient, a family and a community;
- (b) the provision of health and family planning information to individuals and groups;
- (c) the care of a patient and the execution of a nursing care plan for a patient;
- (d) the promotion and maintenance of the hygiene of a patient, a family and a community;
- (e) the promotion and maintenance of the physical comfort, rest, sleep, exercise and reassurance of a patient;
- (f) the prevention of physical deformity and other complications in a patient;
- (g) the supervision over and maintenance of a supply of oxygen to a patient;
- (h) the taking of the blood pressure, temperature, pulse and respiration of a patient;
- (i) the promotion and maintenance of the body regulatory functions of a patient;
- (j) the promotion of the nutrition of a patient, a family and a community;
- (k) the maintenance of intake and elimination in a patient;
- (l) the promotion of communication with a patient during his care;
- (m) the preparation of individuals and groups for the execution of diagnostic procedures and therapeutic acts by a registered person;
- (n) the preparation for and assistance during surgical procedures under anaesthetic;
- (o) the care of a dying patient and a recently deceased patient.

These are the roles enrolled auxiliary nurses have to fulfil at their work place, following their training.

Due to the minimal governmental resources in homes for the elderly, as discussed previously, health care professionals other than nursing staff are seldom employed within the homes (Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012). Thus, the access to health care services of persons with AD is reduced (Borochowitz, 2011), as private health care services are often too costly for these patients. This would imply that nurses are required to adopt multi-faceted roles working in South African governmental homes for the elderly. Their level of preparedness to assume all these roles is questionable. It is found that nurses' training is primarily focused on the physical management of patients. AD specific training is seldom offered. For example, in the United States, all nurses are required to attend training sessions according to the Omnibus Budget Reconciliation Act of 1987 (Castle, 2007). However, merely 7% of the training requirements include specific AD training, with the main focus being physical care. The same is true for the South African nurses, attending a certain number of courses to match their nursing qualification. All courses mainly focus on the physical care of patients, thereby enabling them to meet the patients' immediate needs (South African Nursing Council, 2015). Consequently, nurses feel unprepared in providing care specifically for AD, resulting in a greater focus on physical care, like washing, dressing, grooming and feeding even in homes for the elderly (Sloane et al., 2007). Observations in homes revealed that daily approximately 53% of nurses' time is spent on physical care of the residents with merely 11.8% of their time spent on verbal interactions with patients (Burgio et al., 2001). This shows that limited communication between the residents and nurses can be a reality within the homes for the elderly. It is likely that reduced communication might promote physical restraint and medication as a means to conflict resolution, thereby substituting communication as a problem-solving tool (McCallion, Toseland, Lacey, & Banks, 1999). This could influence the quality of life, social and psychological well-being of persons with mild AD (McCallion et al., 1999), increasing the challenges related to AD care, such as depression and social withdrawal.

The AD care can also be challenging due to the nature of nurses' work-environment and/or the symptoms of persons with mild AD. Challenges related to the work-environment include the earlier discussed resource-shortages and the poor nurse-patient ratios increasing the workload in the homes for the elderly. High nurse-patient ratios have been recorded internationally in different homes for the elderly, for example in the United States (Castle, 2007). It was found that a high nurse-patient ratio results in an increasing workload for nurses. This decreases their overall well-being as a result of increasing levels of work-related stress, reducing their job

satisfaction and nurses' emotional, psychological and physical availability to persons with mild AD, thereby reducing the quality of care for these patients (Mobily et al., 1992). Another factor influencing the care of persons with AD, includes patients' behaviours and perceptions related to their experienced symptoms.

The symptoms of persons with mild AD alters their behaviour and influences their perception of their environment. For example, patients' forgetfulness might result in nurses being accused of lying or stealing patients' belongings. Shigenobu et al. (2002) found that these accusations have a negative impact on the relationships between caregivers, including nurses, and the persons with AD. This is considered as care obstacles, influencing the quality of care and reducing nurses' job satisfaction (Moyle et al., 2011). Accusations also put more mental strain on caregivers, including nurses, thus reducing their mental well-being and increasing the challenges related to the care of persons with mild AD (Shigenobu et al., 2002). Additionally, an increase in patients' aggression, often interpreted to be deliberate and unpredictable, can cause fear, anxiety and stress in nurses, resulting in emotional turmoil and reduced job satisfaction (Brodaty et al., 2003; Edberg et al., 2008; Grant et al., 1996). Emotional turmoil can easily lead to feelings of being overwhelmed, thereby reducing nurses' emotional availability to persons with AD, as they struggle to cope with their own emotions. Emotional turmoil, as a result of patients' behaviours, can influence nurses' attitudes towards persons with mild AD. Nursing staff sometimes assume negative emotions, such as anxiety, frustration and anger, towards persons with AD (Bryans et al., 2003; Brodaty, Draper, & Low, 2003). These negative feelings seem to increase due to patients' behaviours related to the progression of AD and their reduced cognitive abilities (Brodaty et al., 2003; Norbergh, Helin, Dahl, Hellzen, & Asplund, 2006). Negative attitudes, emotional turmoil and the related lack of job satisfaction can be challenging to nurses, potentially resulting in less individualized care and reduced quality of care. Instead of collaborating with patients, nurses might decide on what needs senior citizens have, thereby mostly focusing on their basic physical needs (Perold & Muller, 2000). Nevertheless, the care of senior citizens is multi-faceted and according to the Nursing Act 50, it is the obligation of the nurses to support the patient in all areas of life, to the best of their abilities (South African Nursing Council, 2005).

This obligation can be perceived as great challenge by some of staff members, including nurses, especially if they experience the strain involved in caring for persons with AD and have a lack of psychological support to cope with the strain (Edberg et al., 2008; Grant, Kane, Potthoff, &

Ryden, 1996). These nurses are more likely to present with burnout as discussed earlier (Heyns et al., 2003; Mobily et al., 1992). Other nurses seem to perceive the care of persons with AD as challenging but also mention that through their elaborate care of these patients in homes for the elderly, they become like family. A nursing assistant in the United States for example stated: “I love my patients, I do. And I think they know that, too. You know, ‘cause we’re family to them” (Secrest et al., 2005, p. 94). By becoming patient’s family, nurses are required to love and care for the patient by consoling them during difficult times, thereby keeping them happy and secure. The means in which nurses convert the above challenges to positive and loving perceptions of persons with AD might be as a result of them employing certain coping strategies.

Nurses’ coping strategies can be divided into internal and external nursing factors facilitating the care of persons with mild AD. The internal nursing factors refer to personal factors within each individual nurse, assisting them in reducing their challenges experienced when working with persons with mild AD. The external factors refer to the interactions of nurses with the patients, fellow nurses and work strategies. Aspects of these interactions serve as coping strategies. The internal factors include a hardy personality and making use of cognitive appraisal. A hardy personality is based on three concepts, namely commitment, control and challenge (Florian et al., 1995). A hardy person is

easily committed to what they are doing in their lives, believe that they have some control over the causes and solutions of life problems, and view changes in life and adaptive life demands and challenges as opportunities for growth rather than as threats (Florian et al., 1995, p. 687).

Kobasa (1979) found that this personality type reduces the challenges experienced by study participants. This finding, however, contrasts the findings by Rodney (2000). He examined nurses’ hardy personality in situations where persons with AD would become aggressive and found that their experienced stress was not reduced by the traits related to their personality. The inconsistency between the results could be explainable by the factors examined, other than the personality type.

A hardy personality can furthermore be complimented by cognitive appraisal. According to Folkman et al. (1986, p.993), cognitive appraisal is “the process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-

being and, if so in what ways”. By analysing a challenging situation in terms of the benefits and its effect on one’s well-being, nurses’ convert the AD challenges into opportunities, thereby reducing their levels of experienced stress (Mittelman et al., 2004). It was also found that interventions related to cognitive appraisal, provide caregivers with enhanced coping strategies and reduced the symptoms of depression (Mittelman et al., 2004).

External factors, assisting nurses in coping with the challenges related to AD care, include enhanced relationships between nurses and patients, peer-support between nurses and enhanced work effectiveness, by means of improved communication between nurses. Nurse-patient relationships are enhanced by means of good communication. Sheldon et al. (2006, p.141) went as far in saying that “...communication is a cornerstone of the nurse-patient relationship. The power of effective nursing is strengthened and enriched by good communication”. Good communication, also regularly referred to as patient-centred communication (McCabe, 2004), is necessary to improve caretaking of persons with AD (Perold & Muller, 2000). Good communication can provide patients with information about their daily care-taking routines as well as their medical and/or behavioural management. However, observations in homes revealed that during resident care merely 11.8% is spent on verbal interactions with patients (Burgio et al., 2001). It is also evident that communication in South African homes for the elderly can be challenging due to different first languages (keeping in mind that South Africa has 11 official languages) and cultural backgrounds between senior citizens and nurses. These differences regularly lead to miscommunication and conflict (Perold & Muller, 2000). Due, to the strong association between good communication, nurse-patient relationships and the quality of care, it is of significance for these conflicts to be eradicated. By eradicating these conflicts, nurse-patient relationships will improve and patients are more likely to increasingly appreciate the nurses. In the United States, nursing aids discussed the importance of awards, like appreciation, and its impact on job satisfaction (Castle, 2007). Greater appreciation increases nurses’ job satisfaction, which leads to an improvement of care. Nurses’ job satisfaction will also improve with peer-support. Literature shows that peer-support, as a coping strategy, has led to the formation of formal support or focus groups, assisting nurses to discuss their challenging experiences (Mobily et al., 1992; Sheldon et al., 2006). Internationally nurses seem to perceive peer-support as most helpful, as fellow nurses, working in the same facility, would have enhanced understanding regarding the challenges specific to their work-environment. Discussing these challenges with informed peers seems to assist nurses in resolving the stress related to the challenges (Mobily et al., 1992; Sheldon et

al., 2006). Thus, communication between nurses can be viewed as a means to not only psychologically resolve work related stress but also as a means to enhance work effectiveness.

Work effectiveness can be improved with detailed communication by means of verbal or written reports between nurses, across nursing shifts (Siegel & Young, 2010). However, it is found that nurses merely report on 40% of their activities and only if time allows for documentation (De Marinis et al., 2009). Siegel and Young (2010) found that reports are regularly insufficient, leaving carers, including nurses, with uncertainty about the duties during their shift. Improving communication across shifts can enhance the consistency of care and ensures that duties for the following shifts are clear. This can reduce nurses' stress related to their uncertainties regarding their duties and nurses will not repeat care activities, which are not reported on, thereby working more effectively.

All these coping strategies seem to assist nurses in overcoming the challenges associated with AD care. These strategies allow for nurses to acquire increasing positive attitudes towards persons with AD. Positive attitudes are related to greater job satisfaction and improved provision of care (Moyle, Murfield, Griffiths, & Venturato, 2011). The positive effect on AD care becomes evident in nurses' increased attentiveness, connectedness, friendliness, helpfulness, unobtrusiveness, and respectfulness (Kang, Moyle, & Venturato, 2010) and empathy (Aström, Nilsson, Norberg, Sandman, & Winblad, 1991). Empathy refers to an individual's ability to

place oneself mentally and emotionally in the world of another person, to apprehend another's condition and state of mind, to communicate understanding back to the other and perceive his reaction to it (Aström et al., 1991, p.67).

Nurses' empathy, attentiveness, connectedness, friendliness, helpfulness, unobtrusiveness and respectfulness is however dependent on their personality and their own mental and physical health (Aström et al., 1991).

Considering all of the above, it illustrates that nurses are central to the quality of life of persons with mild AD and that their relationship is vital for the quality of care (Zimmerman et al., 2005). To improve the care of persons with mild AD thus also means caring for the nurses constantly exposed to the challenges of AD care (Zimmerman et al., 2005). This implies that even if nurses are well positioned to adopt many roles in AD care, in the homes for the elderly, it should not be assumed that they will be able to cope with additional roles. It might be

beneficial to the care of patients and nurses to supplement the roles nurses currently assume. Nurses would continue with their daily care activities, involving persons with mild AD, and add additional cognitive and communicative stimulation during these activities. Thereby, the functioning of persons with mild AD is maintained or enhanced, whilst nurses' workload remains constant. The nurses would thus be in the position to provide persons with mild AD with cognitive and communicative stimulation during their daily care activities. Considering the position of the nurses in homes for the elderly, the absence of other health care professionals in the governmental homes for the elderly, the limited resources for persons with AD and the benefits of cognitive and communicative stimulation, there would be merit in enhancing the nurses' skill to provide cognitive and communicative stimulation to persons with mild AD. It would be beneficial if there were therapy stimulation programmes that nurses could apply and utilise within homes for the elderly (Hopper, 2003). In a culturally diverse country such as South Africa, it would be of importance to construct culturally-congruent interventions (Mavundla et al., 2009), considering that cultural differences previously caused conflicts between nurses and patients within South African homes for the elderly (Perold & Muller, 2000). It is suggested that traditional African health care should not be dismissed, but incorporated within the care of persons with AD (Mavundla et al., 2009). Traditional health care can be defined

as the sum total of knowledge or practices whether explicable or inexplicable, used in diagnosing, preventing or eliminating a physical, mental or social disease which may rely exclusively on past experience or observations handed down from generation to generation, verbally or in writing. It also comprises therapeutic practices that have been in existence often for hundreds of years before the development of modern scientific medicine and are still in use today without any documented evidence of adverse effects (Elujoba, Odeleye, & Ogunyemi, 2005, p. 47-48).

In order to develop programmes for nurses on communication and cognition stimulation of persons with mild AD, it is important to learn and know about their beliefs. Programmes sensitive to such perceptions may be more acceptable to nurses and thus have a greater possibility of being implemented.

The application of adequate cognitive and communicative intervention can be achieved by nursing training programmes (Kuske et al., 2009). The significance of these programmes becomes evident in their aim to improve 1) nurses' knowledge related to AD and their self-

confidence as carers, as well as 2) nurses' approaches to management, following a successful intervention programme. These programme goals will be discussed below.

1) Nurses' Knowledge Related to AD and Their Self-Confidence as Carers

One way for nurses to attain knowledge regarding AD and an improved self-concept as carer is by means of educational training sessions (Borbasi, Emmanuel, Farrelly, & Ashcroft, 2011). The following paragraphs will discuss 1.1) existing training programmes for nurses, 1.2) the overall improvement of their knowledge and self-confidence as carers, by means of training programmes for nurses and 1.3) attitude barriers influencing the effectiveness of intervention programmes.

1.1) Existing training programmes for nurses. Research shows that nursing interventions with regards to AD exist. The majority of interventions are focused around the physical care of persons with AD (Kuske et al., 2007). The focus of some interventions is on communication between nurses, patients and family members (Kuske et al., 2007). Other interventions target cognitive stimulation by caregivers. The focus of this study will be placed on the communicative and cognitive interventions. One of the earliest interventions in the respective fields was a Swedish programme (Kihlgren et al., 1993), whereas one of the latest included an Australian programme (Borbasi et al., 2011). Both programmes and other cognitive and communicative interventions will be discussed in a non-chronological order. The order of the programmes was determined by the content thereof, as will become apparent below.

A Floridian programme aimed at improving communication between nurses and persons with AD, by using memory books (Bourgeois et al., 2004). These books intend to aid patients' memories and can be utilised as instructional means during care activities. The four main skills targeted in this programme include, the nurses announcing care activities upon entering patients' rooms, introducing themselves, addressing the patients by their names and waiting five seconds prior to offering physical assistance to persons with mild AD. The memory books would then be used to assist with physical activities or involve patients in conversations. Immediately after the completion of this programme, the nurses demonstrate greater skill in communicating with patients. This programme is very similar to the programme described by Burgio et al. (2001), also utilizing memory books to improve communication between nurses and persons with AD. Both programmes seem to be based on the Nursing Assistant Communication Skills Program (NACSP) and the FOCUSED Program [an acronym describing

the programme elements: face-to-face, orientation, continuity, unsticking, structure, exchanges, and direct (Bourgeois et al., 2004)]. The NACSP and FOCUSED interventions also aim to improve communication between nurses and persons with AD. More specifically, the NACSP training aims at improving the nurses' knowledge of dementia, enhancing their non-verbal and verbal communication skills, introducing memory aids for patients and decreasing patients' problem behaviours. Strategies, which are taught by means of the FOCUS and NACSP programme, include facing patients, using their names and orientating them to the conversational topic. Furthermore, these programmes train the nurses to overcome communication breakdowns by means of offering choices as well as using simple and short active sentences. By means of all four programmes, the communication between the nurses and the patients improved directly post-training (Bourgeois et al., 2004), consequently enhancing the patients' independence (Burgio et al., 2001). However, this improvement was not sustained, as nurses' implementation of communication strategies reduced over time (Bourgeois et al., 2004).

Another intervention is the nurse-led dementia outreach service (Borbasi et al., 2011). It describes an Australian service, which aims at improving the overall personal care of persons with AD. The nurses, who intend to improve the service for persons with AD, work alongside the nursing staff in dementia care facilities, before providing ideas on improving daily care activities. The means of improving the care activities have not been specified other than providing greater person-centered care. It seems that communication is indirectly targeted through this service, however no explicit strategies are mentioned (Borbasi et al., 2011).

The Non-Abusive Psychological and Physical Interventions (N.A.P.P.I.) programme is another programme targeting communication, behaviour management and self-protection skills to reduce assaultive behaviours by patients towards nurses (Palmer & Withee, 1996). This group intervention discusses the nurses' fears with regards to the behavioural problems associated with AD. Following the discussion of fears, the nurses are requested to find means to control the negative behaviour associated with AD. The N.A.P.P.I. programme has suggested that an adjustment of patients' environment and the reduction of patients' physical pain will resolve assaultive behaviour. Further, the nurses, taking part in this programme, mention that patients' anxiety levels increase prior to an assault. Through detection of increased anxiety levels, the nurses can protect themselves and reduce the likelihood of potential assaults (Palmer & Withee,

1996). The means in which communication can assist the nurses to protect themselves has not been clarified.

System of Least Prompts Training is a programme, tested in Kansas, in which is focussed on improving nurses' use of verbal and gestural prompts (Engelman et al., 2003). By means of focusing on verbal and gestural prompts, the programme indirectly targets improved communication between the nurses and the patients as well as maintenance of patients' cognitive abilities. The programme is implemented by nursing staff attending one 30-minute interactive training workshop, before completing their usual dressing routines with the patients. The workshop includes role-playing activities between the nursing staff and the application of strategies, learned during the workshop, with persons with AD. The nurses are requested to use verbal or gestural prompts and provide persons with AD with 5 seconds or more to respond prior to re-prompting. Patients' independent or dependent completion of the dressing task is followed by verbal praise. Subsequent to this workshop, the nurses are requested to provide daily feedback summarizing their application of the learned strategies and the level of assistance that patients required (Engelman et al., 2003). The timespan, in which the nurses are requested to provide feedback regarding their strategy utilisations, is unclear.

A Swedish intervention is another programme that aims at refining the morning activities in nursing homes, by improving communication (Kihlgren et al., 1993). Erikson's integrity promoting theory is the starting point for this programme. The nurses are requested "to promote the patients' experience of trust, autonomy, initiative, industry, identity, intimacy and generativity, in order to facilitate the patients' experience of integrity" (Kihlgren et al., 1993, p. 3). The nurses are therefore equipped with ways to improve their communication, by being more attentive and responsive as a means of facilitating comprehension. Training comprises of 20 hours of lectures and 18 hours of group discussions. Results show that, following the training, the nurses greeted and orientated patients before starting the morning care. The nurses also increased their verbal praise and due to the improved positivity during the morning care activities, the communication between patients and nurses increased as well (Kihlgren et al., 1993).

A programme which was initiated in New York is focused around improving the non-verbal aspects of communication (Agaic, Cohen, & Gomberg, 2002). The programme aims at training the nurses to identify patients' emotions as well as non-verbal mannerisms and the meaning

thereof. The programme was organised around 10 hours of workshop spread over 2 weeks. It seems that, following the workshop, the nurses were able to notice and evaluate patients' affect better. By appropriately responding to patients' affect, positive affect was enhanced in persons with AD thus resulting in patients' improved quality of life (Agaic et al., 2002).

Considering all the above-mentioned training interventions for nursing staff, it becomes evident that these interventions target communication and cognition directly or indirectly. However, all the interventions were developed and employed in countries other than South Africa. The majority of documented or researched interventions were developed in Western and high-income countries. A direct application of these interventions in the South African context might not be sensitive towards the needs of nurses and persons with AD in South Africa, being a middle-income, multi-lingual and multicultural country. Therefore, future AD interventions, specific to communication and cognition, should be developed in South Africa, especially when taking into account the potential improvement of care by means of intervention programmes, as will be discussed below.

1.2) The overall improvement of knowledge and self-confidence as carer, due to training programmes for nurses. The heterogeneity of the above-mentioned programmes makes inter-programme comparisons challenging. Overall, the majority of programmes show an improvement of nursing care, directly following interventions.

More specifically, it has been identified that knowledge of nursing staff improved by attending training sessions (Borbasi et al., 2011; Kuske et al., 2009). Nurses, who feel better trained in AD care, seem to provide better services and portray greater job-satisfaction (Grant et al., 1996; Kada, Nygaard, Mukesh, & Geitung, 2009; Zimmerman et al., 2005). Nurses also claim that they feel more assured and proficient in conducting their tasks, following training sessions (Zimmerman et al., 2005). Thus, training seems to increase the nurses' knowledge and self-confidence in managing persons with AD (Bryans et al., 2003; Borbasi et al., 2011).

The training also seemed to reduce the frequency and degree of stress experienced by nurses (Borbasi et al., 2011). The training can also enhance nurses' awareness regarding their attitudes towards persons with AD, and the effects thereof (Bryans et al., 2003; Norbergh et al., 2006). Negative attitudes can influence the nurses' service delivery unfavourably and, consequently, positive attitudes can enhance their service delivery. Thus, training can aim to improve nurses'

attitudes to enhance nurses' motivation and commitment towards persons with AD (Zimmerman et al., 2005). Additionally, training sessions can provide the nurses with support and coping strategies, which is of significance when working with persons with AD (Brodaty et al., 2003).

Considering the above, it becomes evident that nurse training can benefit patients, due to improved service delivery (Zimmerman et al., 2005). While the benefit for the nurses include enhanced knowledge and skill to treat persons with AD, this also benefits families of these patients, especially when nurses transfer their skills and teach family members means to best approach these patients (Grant et al., 1996). It was however found that the majority of training programmes, which include a follow-up assessment, showed that the positive change in nursing care was seldom sustained over time (Bourgeois et al., 2004; Kuske et al., 2007).

1.3) Attitude barriers influencing the effectiveness of intervention programmes.

The effective application of nursing intervention programmes is determined by the intervention design and the nurses' attitudes towards the programmes. Due to the heterogeneity of the above-mentioned intervention programme designs, the current study will focus on the nurses' attitudes influencing the successful application of intervention programmes.

The nurses regularly perceive interventions as criticism to their current level of care and the individual administering the intervention programme as an intruder, with less background regarding the nursing activities (Borbasi et al., 2011; Teri et al., 2009). The nurses are thus often reluctant to change their routines based on the training courses they attended (Borbasi et al., 2011). Furthermore, the nurses regularly feel that they have no time to provide persons with mild AD, with more individual care (Teri et al., 2009). However, it is often forgotten that, through increasing individual care, patients become more willing to collaborate, making individual care the most pleasurable and time-efficient choice. Another perception influencing the effective application of intervention programmes is the attitude that certain care activities are beyond the nursing scope of practise. This attitude can be directly addressed by homes for the elderly formulating an explicit job description for nursing staff, which includes a variety of care activities (Teri et al., 2009).

All the above-mentioned attitudes can be barriers for the successful application of intervention programmes. Thus, to ensure intervention success and positive changes in nurses'

management, of persons with mild AD, it is of significance to address these negative attitudes. Nurses may acquire more skill and a greater person-centered approach by means of positive attitudes towards intervention programmes, as will be discussed below.

2) Nurses' Approaches to Management, Following Successful Intervention Programmes

Research shows that educational nursing programmes can lead to enhanced person-centered care (Zimmerman et al., 2005). Person-centered care can be defined as respectfully taking into account patients' needs, preferences and principles when caring for them (Morgan & Yoder, 2011). It is a holistic approach to care, as it reaches beyond patients' physical needs and includes patients' social and psychological needs. It refers to patients and health care professionals, including nurses, collectively deciding on the best management option. Patients are thus empowered to be part of their health care decisions. Collective decision-making is only possible if good relationships, built on mutual understanding and trust, exist between health care professionals and patients (Morgan & Yoder, 2011). Person-centered care respects patients' rights to quality of care and life (Koren, 2010). It further aims at making institutions, like homes for the elderly, more homelike and establishing good relationships between family members and nurses. The staff, including nurses, need to be taught means to respond to patients' needs and preferences (Koren, 2010). Nurses need to understand that persons with AD, might wander, scream or appear as aggressive, but that these behaviours can be an expression of unmet desires (Penrod et al., 2007). Instead of merely medicating or physically restraining these patients, the person-centered care would suggest social engagement with patients to establish their needs (Penrod et al., 2007).

Statement of the Problem

Considering the outlined symptoms of AD, AD in South Africa, the possibilities and challenges related to training programmes for nurses as well as the identified importance of cognitive and communicative stimulation of persons with mild AD, a definite need existed for the current study to be conducted. As discussed, there are minimal funds available for the care of senior citizens, including persons with AD, in South Africa. Little funding is available for governmental homes for the elderly and nurses are often the only health care professionals working at these homes. Senior citizens, living in homes for the elderly, are likely to spend a great amount of time with the nursing staff. The nursing staff in these homes are thus well positioned to provide intervention to persons with mild AD in terms of their communication

and cognition. Literature indicates that nursing interventions that directly or indirectly target cognition and/or communication exist. Such intervention programmes can provide nurses with knowledge and enhanced person-centered skills, which decrease their anxiety and stress when caring for persons with AD (Hyer et al., 2010). Further, it can improve the quality of care and life of persons with AD, living in homes for the elderly (Hyer et al., 2010; Porter, Flanders, & Parsons, 2004). However, the majority of AD interventions have been designed and conducted in various countries other than South Africa. It is questionable if international intervention programmes will be appropriate and effective in a country as culturally diverse as South Africa (Mavundla et al., 2009). In South Africa, it would be of importance to construct culturally-congruent interventions (Mavundla et al., 2009), considering that cultural differences between nurses and patients previously caused conflicts within South African homes for the elderly (Perold & Muller, 2000). In order to design and develop context specific training interventions for nurses working in the Tygerberg district (Cape Town, Western Cape), it is necessary to find out what the perceptions of the nursing staff are with regards to the cognition and communication of persons with mild AD.

This South African study thus aimed to determine the perceptions of a group of nurses regarding the care of mild AD, with specific reference to the communication and cognitive abilities of these patients. More specifically this study aimed to examine:

- 1) The nurses' observations of deterioration in persons with mild AD;
- 2) The nurses' perceptions of their roles in caring for persons with mild AD;
- 3) The nurses' perceptions of the factors influencing the care of persons with mild AD;
- 4) The nurses' perceptions on the impact of the governmental homes for the elderly, within the Tygerberg district, on the care of persons with mild AD.

Chapter 2: Methodology

This research followed a qualitative research approach, as it aimed to obtain in-depth knowledge regarding a group of nurses' perceptions associated with AD care. Qualitative research aims to identify all aspects on a topic, by taking into account the perceptions of various individuals (Bless, Higson-Smith & Sithole, 2013). It seeks to explore and describe individuals' perceptions related to human or social problems (Creswell, 2003). The qualitative research approach includes three components, namely 1) the underlying philosophical world view, 2) the research design and 3) the research methods. The three components will be discussed below.

1) The Underlying Philosophical World View

An underlying philosophical world view influences the way that the research is conducted and understood (Creswell, 2003). The philosophical world view, which influenced this study, is the constructivist view. "Constructivists believe that individuals seek understanding of the world in which they live and work. Individuals develop subjective meanings of their experiences – meanings directed toward certain objects or things" (Creswell, 2003, p.8). Various individuals will associate different meanings with certain things and objects, due to their diverse cultural and historical backgrounds as well as their personal experiences. The researcher thus appreciates the variety and complexity of different views and refrains from narrowing and restricting meanings into merely a few categories. Consequently, the research question becomes broader and the questions posed by the researcher to the individuals more open-ended, to allow for multiple different views (Creswell, 2003).

Taking into account the underlying philosophical world view, this research study focused on asking open-ended questions, to ensure that all nurses could discuss their perceptions in an unhindered manner. Furthermore, the nurses were asked to provide reasons for some of their answers, which allowed the researcher to explore the origin of and background to the nurses' perceptions.

2) Research Design

According to Bless et al. (2013), a research design aims to directly answer the research question. This research followed a 2.1) phenomenological, 2.2) cross-sectional, 2.3) non-experimental and descriptive design, as described below.

2.1) Phenomenological Research Design

A phenomenological research design enables the researcher to describe “the lived experiences of individuals about a phenomenon as described by the participants” (Creswell, 2003, p.14). It attempts

...to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer (Moran, 2000, p.4).

Phenomenology attempts to reduce the researcher’s prejudice and former impositions and focuses on the research participants’ experiences and perceptions (Moran, 2000).

More specifically, this research was based on Heidegger’s theory, involving hermeneutic or otherwise known interpretive phenomenology (Wojnar & Swanson, 2007). Hermeneutic phenomenology argues that individuals cannot exist in the absence of their social context, culture, or historical experiences. Heidegger’s concept of *dasein* refers to individuals’ means of existence in the world, to highlight that individuals do not exist in isolation of their contexts. This *dasein* is influencing individuals’ views and providing meaning to personal experiences. The focus of hermeneutic phenomenology lies in integrating the knowledge around a phenomenon, an individual’s information and previously established relevant theoretical data (Wojnar & Swanson, 2007). In terms of this study, it translated to understanding the phenomenon that was the perceptions of a group of nurses, who work in homes for the elderly within the Tygerberg district of the Western Cape, Province of South Africa, regarding the communication and cognition abilities of elderly persons with mild AD.

2.2) Cross-Sectional Research Design

A cross-sectional research design refers to all data being collected within one-time period and aims to immediately collect information relevant to a specific topic (Bless et al., 2013). This study aimed at collecting information regarding the perceptions of nurses caring for persons with mild AD during one particular time period, namely June-July 2016.

2.3) Non-Experimental and Descriptive Research Design

A non-experimental and descriptive research design is used to investigate the perceptions of a selected group towards a particular issue (Creswell, 2003). To attain a good descriptive research design, the researcher should aim to answer the questions: who, when, where, what, why and so what (Grimes & Schulz, 2002). The question ‘who’ will provide the researcher with the actors being described. The question ‘when’ will provide the researcher with a time frame. ‘Where’ will indicate the context in which a phenomenon takes place. The ‘what’-question addresses the activities and events specific to the phenomenon. ‘Why’ provides the researcher with reasons related to the activities and events specific to the phenomenon. The question ‘so what’ establishes the implications that the phenomenon has (Grimes & Schulz, 2002).

Constructivism and phenomenology as theoretical orientations focused the researcher’s attention on descriptions of the nurses’ experiences. A descriptive research design, aiming to investigate all aspects related to the nurses’ perceptions with regards to the cognition and communication of persons with mild AD, was chosen for this study. The descriptive research design enabled the researcher to report on the lived experiences of the nursing staff working within the Tygerberg district of the Western Cape Province of South Africa.

3) Research Methods

A semi-structured interview research method was utilized. It is a combination of structured and unstructured interviewing. An explanation of these two interview structures will clarify which attributes were chosen from which interview method. Structured interviews aim at attaining specific, codable data, to explain and clarify behaviour according to predetermined categories (Denzin & Lincoln, 1994). These interviews follow a fixed interview structure, which cannot be altered. All questions need to be asked in a certain order and no additional questions are permitted. Regular, preestablished answers are provided to the interviewees to choose from within structured interviews. Explicit probes are given to the interviewees to elicit specific information. Unstructured interviews aim to understand various behaviors without imposing predetermined categories in the interview process, as this might limit the content attained during the interviews. During unstructured interviews the researcher can request additional information during the interview and is not bound to a predetermined structure. However, the

researcher might risk obtaining data that is not relevant to the research question, due to the variety of questions that can be asked in the absence of an interview structure (Denzin & Lincoln, 1994).

For this study, a semi-structured interview approach was chosen, incorporating the structure and explicit probes of a structured interview (Bless et al., 2013). The structure was only used as a guideline and could be altered during the interview process. The explicit probes were used as a means to gain specific knowledge regarding the nurses' perceptions. These probes provided the researcher with the freedom to ask any additional questions during the interview process (Bless et al., 2013). Thus, an in-depth knowledge regarding the nurses' perceptions could be gained, whilst following a certain flexible interview structure. In the light of constructivism and phenomenology, the researcher could aim to determine the essence of individuals' perceptions and experiences within their various contexts, without being constricted by the interview structure. The means in which nurses were selected to participate in the research study, will be discussed below.

Selection Strategy

This study used nonprobability sampling as principal sampling technique, which allowed for the researcher to determine the perception of a very specific group of nurses working in the Tygerberg district. Two specific types of nonprobability sampling were used, namely convenience sampling for the homes and purposive sampling for the nurses. A convenience sample refers to a group, representative of a research population, who are chosen by the researcher based on their availability and accessibility (Kothari, 2004). The research sites in the Tygerberg district of the Western Cape Province of South Africa were chosen based on the financial means of the researcher. As this research was entirely funded by the researcher, it was financially viable for her to choose homes in relative close proximity to her. Additionally, the research sites were chosen as various researchers previously demonstrated the lack of resources for governmental homes for the elderly and persons with mild AD in South Africa (De Jager et al., 2015; Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012; Borochowitz, 2011). This led to the researcher's interest in conducting her research in governmental homes for the elderly, identifying the means in which nurses cared for persons with mild AD with the resources they have available.

Purposive sampling aims at understanding the experiences of a selected group, by choosing ‘information rich’ cases providing most insight into the research topic (Devers & Frankel, 2000). This study aimed to determine the perceptions of a group of nurses regarding mild AD, with specific reference to the communication and cognitive abilities of these patients. The group of nurses examined, included enrolled auxiliary nurses. Enrolled auxiliary nurses were chosen as they were the most prevalent group of nurses in the participating homes for the elderly, necessary for attaining information-rich data.

Governmental Homes for the Elderly

The discussion in Chapter 1 illustrated that the majority of homes for the elderly in South Africa are funded by non-governmental organisations (Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012; Department of Social Development, 2005). This study focused on governmental homes for the elderly and defined these homes as homes subsidized by the government. In 2001, 32 of the 96 homes for the elderly, in the Western Cape Province of South Africa, received subsidies from the government in the Western Cape, Province of South Africa (Department of Social Development, 2005). The remaining homes were entirely funded by non-governmental organisations. The subsidies by the government are fixed and are given to persons of low socio-economic backgrounds, unable to pay the expenses of the homes for the elderly (Department of Social Development, 2010). These subsidies per person are however insufficient to cover the living expenses of the residents in the homes for the elderly, making it more challenging to provide a suitable level of care in the governmental homes (Department of Social Development, 2010). These challenges are unique to the governmental homes for the elderly, distinguishing them from the homes entirely funded by non-governmental organisations.

Selection Criteria for the Homes for the Elderly

For the purpose of this study, the research sites had to fulfil the following criteria:

- The home for the elderly needed to be a governmental institution, receiving subsidies from the government.
- The home for the elderly needed to be situated within the Tygerberg district, in the Cape Town area, in relative close proximity to the researcher’s work- and home-environment.

Description of Governmental Homes for the Elderly

A brief description of the governmental homes for the elderly is provided in the following table.

Table 1-1: Description of the homes for the elderly

Home for the Elderly	Socio-economic status (SES) in the area	Socio-economic back-grounds of residents	Total number of residents in the home	Residents with AD	Residents with AD relative to the total number of residents in the homes (provided as percentage)	Total number of nurses employed in the home	Number of nurses per shift (divided into day shift, night shift and weekend shift)
1	Lower SES	Low	30	27	90%	5	1 to 2
2	Lower SES	Low	98	56	54,88%	8	2 to 3
3	Lower SES	Low-Middle	104	23	22,12%	18	6
4	Lower SES	Low	124	28	22,58%	8	2 to 3
5	Lower SES	Low	150	20	13,33%	12	3 to 4
Average percentage of persons affected by AD relative to the number of residents living in the homes for the elderly:					40,58%		

As evident by the table above, all homes for the elderly were situated in areas that can be described as having a low socio-economic status. The number of residents within the homes varied between 30 to 150 residents, with most of them being from lower socio-economic backgrounds. In the homes for the elderly, the number of residents affected by AD varied

between 13,33% to 90% residents. One to six nurses were responsible for the care of all residents, during each shift, including day-, night- and weekend shift.

Participants

A convenience sample was recruited, comprising of nurses caring for persons with mild AD within five homes for the elderly, in the Tygerberg district of the Western Cape Province of South Africa.

Participant Selection Criteria

The selection criteria aimed to ensure that the research participants formed part of the population that the researcher intended to study. Further, it aimed to ensure that the participants were information-rich sources and that the data obtained from them would answer the underlying research question. The biographical questionnaire, as discussed below, aimed to ensure that participants conformed to the selection criteria. For the purpose of this study, the participants had to fulfil the following criteria:

- The participants had to be enrolled auxiliary nurses (ENAs), working at one of participating governmental homes for the elderly, within the Tygerberg district of the Western Cape Province of South Africa. Only ENAs were included within the study, aiming to ensure a similar nursing training background among the participants. This was of importance to the researcher to ensure that possible heterogeneity of nurses' responses is due to their various perceptions and experiences and not the result of different training backgrounds.
- As previously mentioned, enrolled auxiliary nurses were chosen as they were the most prevalent group of nurses in the participating homes for the elderly, necessary for attaining information-rich data.
- The participants were required to be proficient in English or Afrikaans, as the interviews were conducted in the specified languages, based on the researcher's linguistic abilities. Due to the nature of a phenomenological research design, the researcher decided against employing an interpreter, as biases could arise due to interpretation. Eventhough the interpreters would translate to their best ability and understanding, their understanding of the participant's message might differ from the actual message by the participant, which would have influenced the research results, preventing a true representation of the nurses' perceptions. This would affect the phenomenological nature of the research study, by failing to present "the lived experiences of individuals about a phenomenon as described

by the participants” (Creswell, 2003, p.14).

- The participants had to have a year of experience of providing care to persons with mild AD. This provided the participants with the opportunity to gain sufficient skills and knowledge related to AD care (Bobay, Gentile & Hagle, 2009). These skills and knowledge enabled the participants to reflect on and respond to the questions during the semi-structured interviews.

Participant Description

A brief description of the ENAs, who participated in this study, is provided in the following table.

Table 1-2: Biographical information describing the study participants

Participant	First language	Interview language based on the participant’s fluency in English or Afrikaans	Level of nurse education	Years of working experience with mild AD in years
N1	Xhosa	English	ENA	5 years and more
N2	Afrikaans	Afrikaans	ENA	5 years and more
N3	Afrikaans	Afrikaans	ENA	1 to 5 years
N4	Afrikaans	Afrikaans	ENA	5 years and more
N5	Afrikaans	Afrikaans	ENA	1 to 5 years (exactly 1 year)
N6	Xhosa	English	ENA	5 years and more
N7	Afrikaans	Afrikaans	ENA	5 years and more
N8	Afrikaans	Afrikaans	ENA	5 years and more
N9	English	English	ENA	1 to 5 years
N10	Afrikaans	Afrikaans	ENA	5 years and more
N11	Afrikaans	Afrikaans	ENA	5 years and more
N12	Afrikaans	Afrikaans	ENA	1 to 5 years

As evident by the information provided in the table, all participants were enrolled auxiliary nurses. Nine participants were Afrikaans first language speakers, which resulted in Afrikaans being the dominant language in which most interviews were conducted. Merely three interviews were conducted in English, of which two were with participants who were Xhosa first language speakers, with sufficient English language skills (as determined by the researcher), allowing for their inclusion in the study. Furthermore, all participants had worked with persons with mild AD for a minimum of a year. Eight participants had five and more years of experience working with persons with mild AD. Three participants reported to have between one and five years of experience and one participant (N5) reported to have worked with persons with mild AD for exactly a year. Considering all of the above, it becomes evident that all participants fulfilled the participant inclusion criteria, proposed by this study. The researcher had no relationship with the participants prior to the interviews, as all the participants were unknown to the researcher.

Selection Procedures

- The managers of the predetermined seven governmental homes for the elderly, within the Tygerberg district, were informed about the study and asked for permission to conduct research in their care facilities.
- Of the seven homes invited to participate in this study, five accepted the invitation.
- Two of the five consent-giving homes for the elderly were approached for piloting the semi-structured interview guide. Based on the fact that no adjustments to the interview guide were made, these interviews were regarded as suitable for inclusion in the main study.
- These pilot study sites were chosen randomly from the list of consenting homes.
- The researcher distributed biographical questionnaires to all enrolled auxiliary nurses working within these homes. These questionnaires were completed with the help of the researcher.
- From all the consent-giving homes, all participants who met the selection criteria, as determined by the biographical questionnaire, were invited to participate in this study (as described in more detail under the heading “Main Procedure”).
- Twelve of the 14 participants, who met the selection criteria, were willing to participate in this study.
- The two ENAs, who declined the invitation to participate in the study, were based in two

different homes for the elderly. After completion of the biographical questionnaire and familiarization to the research topic, they felt too unprepared in terms of their AD knowledge to participate in the study.

Materials and Instrumentation

The materials and instrumentation utilised within this study comprised of a semi-structured interview guide, biographical questionnaire, the researcher and mechanical instruments.

Semi-Structured Interview (Appendix 1)

A semi-structured interview guide, developed by the researcher, was used to identify the nurses' perceptions regarding AD care, during the mild stage of the condition. The interview guide contained a series of questions that explored the participants' perceptions regarding mild AD and the communication and cognition of persons with mild AD. It included mostly open-ended questions, which allowed participants to freely share their experiences with the researcher. If any uncertainties arose or clarifications were necessary during the interview process, the researcher was free to ask additional questions, not outlined on the interview guide. The interview guide was developed according to the guidelines established by Turner (2010), who suggests that appropriate qualitative research questions include the following features: (1) the wording of questions should be open-ended; (2) the questions should be phrased neutrally, thereby limiting the impact that wording might have on participants' responses; (3) questions should be asked consecutively and not all at once; and (4) the questions should be clearly formulated or phrased. Patton's (2002) discussion of the various types of questions also influenced the development of the interview guide. Patton (2002) identifies six types of questions, namely: background- or demographic-; behaviour; opinion- or value-; feelings-; sensory experience- and knowledge questions. Background or demographic questions elicit information regarding the participants' name, level of education and home language (Patton, 2002). For the purposes of this study, a biographical questionnaire was used to obtain this information. The demographic questions also allowed the researcher to confirm whether the nurses were eligible participants for this study based on the selection criteria. Furthermore, these demographic questions focused on the work experience of the nurses and the extent to which these participants previously worked with patients with mild AD. Answers to these questions were elicited by means of the biographical questionnaire and the interview. The behavioural questions determined the duration and frequency with which nurses worked with persons with mild AD. Further information about the nurses' behaviours became evident from

the opinion or value, feeling and sensory experience questions. Opinion or value questions addressed nurses' evaluation of their experiences related to mild AD (Patton, 2002). The discussion of experiences was closely linked with the feelings and senses related to these experiences (Patton, 2002). The knowledge questions prompted the discussion of the nurses' factual knowledge related to the research topic (Patton, 2002). This study included the opinion or value, feelings, sensory experience and knowledge questions below, developed following an extensive literature research:

- Please tell me about your experience of caring for persons in the early stage of the AD condition.
- What aspects of caring do you find easier, in the early stages of AD?
- What is most difficult for you in caring for AD patients, in the early stages of the condition?
- In your experience, what are the major problems that AD patients are struggling with, in the early stages of the condition?
- Please tell me about your experience of communicating with patients with mild AD.
- What aspects of communication with a patient with early stage AD do you find easier?
- What aspects of communication with a patient with early stage AD is difficult for you?
- If you think back to your interactions with early stage AD patients, how would you describe their reaction when you spoke to them?
- What do you think can help these patients to understand when somebody is speaking to them?
- Do you think that there are certain things that may confuse patients with early stage AD when somebody speaks to them?
- In your experience, what might confuse patients with AD when somebody speaks to them?
- Please tell me about the problems in cognition that have you noticed in persons with early stage AD?
- Please tell me about what you learned about AD during your nursing education?
- What do you think is the nurse's role in caring for a patient in the early stages of AD (within the context of a home for the elderly)?
- Is it part of your role to help patients with their communication and cognitive problems?
- Who do you think should help patients with early stage AD with their communication and cognition problems?

These questions aimed at determining the nurses' perceptions regarding the care, communication and cognition of persons with mild AD. Furthermore, these questions provided the researcher with some background regarding the nurses' knowledge of mild AD. Health professionals' knowledge related to mild AD play an important role in the quality of care provided to these patients (Smyth et al., 2013), thus providing support for the inclusion of these questions. These questions became significant determiners describing the experiences of nurses working with persons with mild AD in governmental homes for the elderly, in the Tygerberg district.

The Biographical Questionnaire (Appendix 2)

Biographical questionnaires can determine the educational, language, family, economic and personal background of participants (Enslin, Button, Chakane, de Groot & Dison, 2006). The biographical questionnaire gathered information regarding the participants' language background, nursing qualification and years of experience working with persons with mild AD, as these were the factors of relevance to the research question and inclusion criteria. The participant selection criteria aimed to ensure that the research participants formed part of the population that the research aimed to study and that the data answered the underlying research question (Patton, 2002).

The Researcher

In qualitative research, the researcher assumes the role as main instrument with regards to data collection and analysis. For repeatability of the qualitative research, demographics across researchers should be comparable. It is thus important for the researcher to provide some background with regards to her qualifications, experience, assumptions and expectations within the study domain (Shenton, 2004).

This study was performed by a SLT, who completed her four-year professional bachelor degree in speech- and language therapy at Stellenbosch University. During her undergraduate training for the degree, she attended an advanced seminar course on AD. Following her course, she started working as an undergraduate student with dementia patients in governmental homes for the elderly and formed the perception that these patients could receive improved cognitive and communicative interventions. This observation was followed by extensive literature research which showed that cognitive and communicative intervention can benefit the persons with mild AD. Literature also illustrated that the majority of existing nursing interventions, specific to

cognitive and communicative stimulation of persons with AD, were designed and conducted in Western and high-income countries, which led to the research question about the perceptions of nurses in South Africa with regard to the communication and cognition of persons with mild AD.

The researcher's knowledge and experience, specific to research methodologies, was limited to her undergraduate research dissertation and two methodology courses which she attended during her undergraduate training. In preparing for her postgraduate study, she built research specific skills and knowledge by watching video-taped podcast of a doctoral methodology course and attending a postgraduate research course, focused on qualitative research designs. Supplementary, this researcher read multiple articles and books discussing qualitative research approaches, most of which are cited in this chapter.

It is also of significance to gain some insight regarding the researcher's expectations and assumptions, as it provides more information about the researcher's motivation to conduct this study. Further it assists the researcher in reporting on the perceptions of the participants, as truthfully as possible, always reflecting back to her own perceptions. It serves the purpose of making the researcher more aware of her own assumptions and expectations regarding the field of study and should help her in preventing her own assumptions from influencing her interpretation of the participants' stories. This reflection during the analysis process is called bracketing (Chan, Fung, & Chien, 2013). The researcher's assumptions and expectations related to her research topic can be referred to in appendix 6 under the heading "The Researcher's reflection". Due to the elaborate nature of the reflection, the researcher decided to exclude it from the body of the research text and instead attach her reflection as an appendix.

Mechanical Instruments and Application Thereof in This Research Study

The mechanical instruments used in this study included a voice recorder and computer. Permission was obtained from all participants allowing for interviews to be voice recorded. Voice recordings permitted subsequent transcriptions and revisiting of interview content (Halcomb & Davidson, 2006). This reduced the risk of vital information being lost in the interview process. The researcher transcribed the voice recordings using a computer and the Free NCH Sound and Audio Software. This software allowed for reducing background sounds in audio-recordings as well as the adaptation of the audio-speed. The Weft QDA (Qualitative Data Project) was used as data analysis software and aided the generation of initial codes, the

search for themes, the revisiting of themes as well as the defining and naming of themes (Braun & Clarke, 2006), as will be discussed below. Microsoft Word was used as a word processing programme and was employed for the writing up of the dissertation report.

Procedures

Pilot Study

A pilot study was conducted in order to evaluate the interview guide and to prepare the researcher for the interview process. Peat, Mellis, Williams and Xuan (2002) reported that pilot studies are an effective way to identify and remedy vagueness and ambiguity of materials intended for use during data collection.

The pilot interviews were conducted at two homes for the elderly, with two participants in each home, in the same manner in which the main study was conducted. The two homes for the elderly approached for the pilot study, were randomly chosen from the five consent-giving homes. Following the selection of homes for the elderly, the managers of the pilot study homes were consulted and it was confirmed that research could be conducted at the workplace of the nurses, during the nursing shifts. After obtaining permission, two eligible participants in each pilot study home were chosen randomly. All eligible nurses were grouped into an Afrikaans- or English-speaking group (according to their reported home language or language they felt most proficient speaking) and received a number. One number within each language group was randomly selected, and the corresponding two nurses, within each home, were then invited to participate in the pilot study. The interview commenced, by giving the participants a short definition of communication, cognition and mild AD. Communication was defined as the way patients speak and understand and cognition as the way they think and remember. Mild AD was defined as the beginning stage of the disease, usually shortly after diagnosis. Subsequently, the researcher was able to explore the nurses' perceptions of mild AD, by following the interview guide and asking supplementary questions where clarifications or additional information was necessary. Once the researcher suspected that participants spoke about the moderate or severe stage of AD, explicit probes were used redirecting the discussion towards the mild stage of AD. Some of the probes included "Are you speaking about patients with mild or beginning stage AD when you say...?", "Is this the reality for patients with mild or beginning stage AD?" or "What stage of AD are you referring to when you say this?". Following the completion of the semi-structured interviews, the consenting participants were asked to provide feedback regarding the interview in order to identify incomprehensible, vague, unnecessary

and/or ambiguous questions. The pilot study also aided the researcher in evaluating the order of the questions in the interview guide and assisted in determining whether the questions were suitable in eliciting the desired responses or if rewording of questions needed to be made, for the main study. Following the feedback of the participants, it became evident that no adjustments to the interview were necessary. The pilot study participants were thus also included in the main study.

Main Procedure

The remaining consent-giving homes for the elderly were approached for participation in the main study. Each manager in the corresponding homes was consulted and confirmed that research could be conducted during the nursing shifts. Once confirmation was obtained from the managers, the researcher distributed the biographical questionnaires to all the enrolled auxiliary nurses to identify all eligible participants, as specified by the participant selection criteria. All eligible participants then received participant information sheets and consent forms (refer to Appendix 3 for examples of documents in English and Afrikaans). The participant information sheets explained the nature of the research to the participants. The researcher described the content of each section on the information sheets to each nurse individually. Uncertainties identified by the participants regarding the research were clarified by the researcher. Participants were asked if they were willing to participate in the study and permitted voice recordings. Finally, they were requested to complete the consent form accordingly. All eligible nurses within each home for the elderly who were willing to participate were interviewed for as long as it was necessary to discuss all of the questions of the interview guide. The average duration was approximately 35 minutes. The longest interview was 55 minutes and the shortest interview was completed in 22 minutes. The interviews were initiated by giving the participants a short definition of communication, cognition and mild AD. Communication was defined as the way patients speak and understand and cognition as the way they think and remember. Mild AD was defined as the beginning stage of the disease, usually shortly after diagnosis. Subsequently, the researcher was able to explore the nurses' perceptions of mild AD, by following the interview guide and asking supplementary questions where clarifications or additional information was necessary. Once the researcher suspected that participants spoke about the moderate or severe stage of AD, explicit probes were used redirecting the discussion towards the mild stage of AD. Some of the probes included "Are you speaking about patients with mild or beginning stage AD when you say...?", "Is this the reality for patients with mild or beginning stage AD?" or "What stage of AD are you referring to when you say this?". Each

nurse was interviewed once and member checking mostly commenced throughout the interviews with the nurses, to ensure the quality of the preliminary research findings (Carlson, 2010). According to Carlson (2010), member-checking can occur following data analysis or throughout the interview process. Member checking provided the nurses with an opportunity to indicate agreement or not with aspects of the preliminary research results, thereby reassuring that the preliminary findings and their lived experiences were congruent. Throughout the member checking process, the researcher repeated the nurses' messages, requesting if her understanding was appropriate or if nurses could provide clarifications for the researcher to best comprehend their lived experiences. Data collection terminated once all eligible nurses, willing to participate in this study, were interviewed. Subsequent to the data collection, data analysis commenced. The researcher transcribed all the voice recording using the Free NCH Sound and Audio Software. Upon completion of the transcriptions, the researcher employed the Weft QDA (Qualitative Data Project) assisting with the generation of codes, which evolved into themes during later stages of data analysis, as will be discussed in more detail below. Two nurses were contacted telephonically, following the data analysis, for additional member checking, to obtain clarifications overlooked during the interview. Following the final member checking, the finalisation of the research results and the writing up of the dissertation report, the nurses at all of the participating research sites were provided with feedback regarding the findings of the study. Each nurse and manager received a DVD with a video that described the findings and recommendations of this research study.

Data Coding and Analysis

The data collected from the interviews was analysed qualitatively, using thematic analysis. Thematic analysis describes the method that identifies, analyses and reports themes found in data. The specific thematic analysis utilised in this study included components of inductive thematic analysis, latent themes and constructionist epistemology (Braun & Clarke, 2006).

Inductive Thematic Analysis

Inductive thematic analysis is data-driven. This approach identifies the themes obtained during data collection. The themes are thus related to the data and not previous research (Braun & Clarke, 2006).

Considering the phenomenological background and constructivist worldview, this research aimed at understanding and analysing the perceptions of the nurses, irrespective of previous research findings. Merit for this study was grounded in the fact that the perceptions of enrolled auxiliary nurses, in the Tygerberg district of the Western Cape Province of South Africa, towards mild AD have not yet been examined. Therefore, it was of interest to the researcher to identify themes linked to the data itself, thereby gaining a greater perspective of the experiences of the nurses within the Tygerberg district.

Latent Themes

Latent themes are the themes underlying the explicitly stated content of the participants' interviews. These themes examine the core ideas, perceptions, conventions and conceptualizations underlying the semantic content found within data (Braun & Clarke, 2006). Considering the phenomenological background and constructivist world view, this research did not only focus on the semantic content of the interviews, but aimed at identifying reasons to describe and explain the nurses' experiences, with regards to mild AD. Data analysis took into account the semantic content as well as the nurses' social and cultural backgrounds and histories. Analysis beyond semantic content attempted to provide this research with an in-depth understanding of the nurses' experiences.

Constructionist Epistemology

The constructionist epistemology refers back to the philosophical worldview, discussed previously. It states that "meaning and experience are socially produced and reproduced, rather than inhering within individuals" (Burr, 1995 as cited in Braun & Clarke, 2006, p. 84). This provided reason for the data to be analysed beyond semantic level, taking into account the nurses' backgrounds and previous experiences, as discussed before.

All the above factors influenced the way in which the data was analysed. The procedure of thematic analysis was divided into six steps, namely 1) the familiarization with data, 2) the generation of initial codes, 3) the search for themes, 4) revisiting themes, 5) "defining and naming themes" and 6) the production of a report (Braun & Clarke, 2006). These steps will be described in the following paragraphs.

1) The Familiarization with Data

In this study, data familiarization commenced with the researcher conducting the interviews herself, followed by her transcription of the audio recorded interviews to written documents. The researcher transcribed the data herself to maintain and protect confidentiality of the nurses (Bless et al., 2013). Following the transcription, the data was read multiple times, in an active manner, to identify patterns and meaning (Braun & Clarke, 2006). Repeated reading ensured that the researcher was familiar with the data she had collected.

2) The Generation of Initial Codes

For the purpose of this study, a list of interesting ideas, found within the data, was outlined. These ideas shaped the initial codes obtained from the data. Once initial codes were found, all data extracts were paired up with these codes. Further verification took place by ensuring that the different data extracts sharing a single code, related to each other. Additionally, the same data extract was occasionally matched to different codes (Braun & Clarke, 2006).

3) The Search for Themes

Once codes were found for all data extracts, various codes were combined to form an all-encompassing theme. This required the researcher to identify the relationships between the codes and establish the main themes (all-encompassing theme) as well as the sub-themes (different themes forming fragments of the all-encompassing theme) (Braun & Clarke, 2006).

4) Revisiting Themes

Each potential theme was revisited and the researcher decided if the identified themes really were substantial themes. Firstly, the researcher analysed if all coded data extracts within a singular theme, formed a coherent whole. Secondly, the researcher evaluated the validity of all themes, as a representation of the data set as whole (Braun & Clarke, 2006).

5) “Defining and Naming Themes” (Braun & Clarke, 2006, p.92)

For the researcher to define her themes, she needed to identify the essence of the themes and provide reasons for their significance. The researcher needed to clearly state the features of each theme, defining what the themes entailed and what they did not represent. Following the theme definition, the researcher attempted to name her themes concisely, thereby providing the reader with an idea about the essence of the theme (Braun & Clarke, 2006).

6) The Production of the Report

Following the defining and naming of themes, the researcher linked all the themes with each other and started writing a report. The report included all the results found by means of the data analysis (Braun & Clarke, 2006). The results will be presented and discussed in the next chapter.

Trustworthiness of the Data Analysis

Carlson (2010) states that the variations of study design and protocol in qualitative research studies may generate problems with regards to the trustworthiness of the research. In addition, the focus of qualitative research lies in the identification of in-depth experiences of the participants. However, the subjective experiences of the researcher as well as the researcher's study aims might guide her analysis and can easily lead to impositions of expected lived experiences of participants, resulting in miscommunication between the participants and the researcher. To decrease the probability of such misunderstandings, the researcher attempted to ensure trustworthiness by taking into account 1) credibility, 2) transferability, 3) dependability and 4) confirmability (Morrow, 2005).

1) Credibility

Credibility describes the internal consistency of the research findings. Credibility within this research study was ensured by prolonged interviews with participants, member checking, as described above, researcher reflexivity, thick descriptions and multiple triangulation. Prolonged interviews suggest that enough time was allowed and provided by the researcher, necessary to discuss all the questions of the interview guide. Researcher reflexivity refers to the researcher's constant evaluation and adaption of her research study and findings (Shenton, 2004). 'Thick' descriptions were employed to describe the participants' experiences of the phenomena as well as "the contexts in which those experiences occur" (Morrow, 2005, p.252). This study also included multiple triangulation, namely data source and theoretical triangulation. Data source triangulation was achieved by taking into account the dimension of time, place and person (Thurmond, 2001). The dimension of time entailed the interviews during day-, night- and weekend-shifts. The interviews within the five homes for the elderly, analysed through the lens of the Western Cape context (province of South Africa), accounted for the aspect of place, whereas the 12 nurses fulfilled the dimension of person. Theoretical

triangulation was achieved by the extensive literature search, including various theories and hypotheses (Thurmond, 2001) during the analysis of the nurses' perceptions with regards to AD.

2) Transferability

Transferability refers to the degree to which the reader is capable of generalizing the research findings to his or her own context. This research study aimed for transferability by providing extensive information about the researcher, the study context, procedures, research participants and researcher– participant relationships. This information enables the reader to judge in what way research findings may be transferable (Morrow, 2005).

3) Dependability

Dependability refers to the research procedure, which should remain consistent across time and data analysis (Morrow, 2005). The research procedure should be explicitly documented, thereby increasing the chances of other researchers repeating the study. This research study aimed for dependability by reassuring that the suggested research procedure, design and analysis techniques were conducted as proposed.

4) Confirmability

Confirmability refers to the researcher's aim to present findings as objectively as possible, describing the essence of the phenomenon being researched and not the researcher's experiences and biases.

It is based on the perspective that the integrity of findings lies in the data and that the researcher must adequately tie together the data, analytic processes, and findings in such a way that the reader is able to confirm the adequacy of the findings (Morrow, 2005, p.252).

This research study aimed for confirmability by providing multiple participant quotes and the conversational context in which these quotes occurred.

Ethical Considerations

- Approval of the Health Research Ethics Committee (HREC) at Stellenbosch University was obtained prior to commencing research (please refer to appendix 5 for the approval letter). The HREC reference number for this research was S16/04/076.

- Written informed consent was obtained from the managers working at the respective homes for the elderly and from each participant prior to the study. The participant information sheets and informed consent forms discussed the nature of the study and confirmed that participation was completely voluntary.
- All the participants were informed that confidentiality was guaranteed and that the rights of the participants were protected. Data for each participant was coded by number to safeguard the confidentiality of information and stored in a secure, locked facility. All participants are referred to by their assigned numbers (1-12) combined with a ‘N’, an abbreviation for ‘nurse’ (e.g. N1 or N9), in this research thesis. Future publications or presentations involving this research will continue using these codes specific to each participant. Confidentiality was also maintained by merely indicating that all the homes were in the Tygerberg district, with no indication of the names of these institutions. These sites are only known to the HREC, the supervisor and co-supervisor whereas the names of the participants are only known to the researcher.
- The selected participants were informed of all aspects of the study. Participation was voluntary and participants were allowed to withdraw participation at any time, without facing any negative consequences.
- The procedures of the study imposed no risks to the participants.
- The results of the study were made available to the participants as well as to the HREC in the form of progress reports.

Chapter 3: Results and Discussion

The semi-structured interviews with the nurses and the analysis according to the phenomenological approach, resulted in a variety of different findings. To orientate the reader throughout the dissertation, the results and discussion section consistently follows a specific structure. Each of the four main themes and the corresponding subthemes are introduced with a table. The table provides the reader with an expectation of the content to be covered in the subsequent sections. Furthermore, most subthemes, except two short and precise themes, are concluded with a summary of the discussed findings as well as an indication of its relevance to a SLT, working in the South African context. This provides the reader with an overview of the findings and furthermore highlights the importance of all subthemes to a SLT, thereby emphasising its significance in this study.

Throughout the discussion of the themes and the corresponding subthemes, the researcher used verbatim English and Afrikaans quotations, provided by the nurses during the semi-structured interview process. The original Afrikaans quotes are accompanied by appropriate English translations. All quotations are used in an attempt to ensure confirmability of the study results, thereby assuring trustworthiness of the research study. To emphasise key words within the quotes, the font is bolded. The capitalised words found in brackets, following some quotes, indicate an action or behaviour of the nurses. Additional brackets, without capitalisation, were used to provide missing words or clarify quotations by providing a context, given by the participants in earlier statements. To draw attention to specific nurses and their statements, the nurses' codes (as explained below) are underlined throughout the text. Key words within the body of the text, other than the quotes, have been italicised.

The abbreviations used within the body of the text include AD, N, SLT, SLTs and C. These abbreviations refer to the following:

- AD is Alzheimer's dementia.
- N is nurse and the numbers following the 'N' are the codes given to the different nurses to protect their identities.
- SLT is speech-language therapist and SLTs refers to the plural thereof.
- C is the researcher.

It is also important to note that throughout the results and discussion section, reference is made to the moderate and severe stages of the condition. Even though the researcher did not intend to investigate these stages of the condition, various nurses continuously referred to them. Explicit probing, as described in chapter 2, was required to promote responses specific to the mild stage of AD. However, due to the high frequency of responses referring to the moderate and severe stages of AD, the researcher decided to mention these stages whilst still focusing the main body of the research text on the mild stage of AD. By taking this approach, the researcher is following the phenomenological approach and the constructivist view, allowing and appreciating the variety and complexity of different views and refraining from narrowing and restricting meanings (Creswell, 2003). The following research text is thus truly representative of the findings obtained in this study.

The findings of this study are organised into four main themes, namely 1) the nurses' observations of deterioration in persons with mild AD, followed by 2) the nurses' perceptions of their roles in caring for persons with mild AD, 3) the nurses' perceptions of the factors influencing the care of persons with mild AD as well as 4) the nurses' perceptions on the impact of the governmental homes for the elderly, within the Tygerberg district, on the care of persons with mild AD, as indicated in the table below. Each of these themes and subthemes will be discussed in the pages that follow.

Table 2: Summary of the main- and subthemes discussed in Chapter 3:

<p><u>1) The nurses' observations of deterioration in persons mild AD:</u></p> <ul style="list-style-type: none"> -Reported challenges relating to the motor abilities of persons with mild AD -Reported memory changes in persons with mild AD -Reported 'additional' cognitive changes in persons with mild AD (i.e. tendency to create their own world, changed executive functioning and disorientation) -Reported communication changes in persons with mild AD -Reported emotional and personality changes in persons with mild AD
<p><u>2) The nurses' perceptions of their roles in caring for persons with mild AD:</u></p> <ul style="list-style-type: none"> -The nurses' need to assist with the physical care of persons with mild AD -Nurses' roles in providing persons with mild AD with memory stimulation exercises -Nurses' role in assisting persons with mild AD with their cognitive limitations

-Nurses' role in assisting persons with mild AD with their communication -The nurses need to provide emotional care to persons with mild AD
<u>3) The nurses' perceptions of the factors influencing the care of persons with mild AD:</u> -The internal nursing factors <i>facilitating</i> the care of persons with mild AD -The external nursing factors <i>facilitating</i> the care of persons with mild AD -An additional factor <i>inhibiting</i> the care of persons with mild AD
<u>4) The nurses' perceptions on the impact of the governmental homes for the elderly, in the Tygerberg district, on the care of persons with mild AD:</u> -Reported need for additional resources and nurses to facilitate greater care in homes for the elderly -Advantages of AD care in homes for the elderly -Disadvantages of AD care in homes for the elderly

Theme 1: The Nurses' Observations of Deterioration in Persons with Mild AD

As apparent in the table below, the nurses discussed deterioration according to the following subthemes: 1.1) motor abilities, 1.2) memory changes, 1.3) 'additional' cognitive changes, 1.4) communication changes as well as 1.5) emotional and personality changes. For the purpose of this study, memory changes will be discussed independent of other cognitive changes, as all the nurses suggested its significance and most rapid deterioration. However, to acknowledge that memory is also a cognitive function, the remaining cognitive changes (i.e. tendency to create their own world, changed executive functioning and disorientation) will be referred to as 'additional' cognitive changes.

Table 2-1: Summary of the nurses' observations of deterioration in persons mild AD:

<u>1.1) Reported challenges relating to the motor abilities of persons with mild AD:</u> -The effect of maintained motor ability but reduced cognitive functioning -Potential motor changes in persons with mild AD
<u>1.2) Reported memory changes in persons with mild AD:</u> - General description of memory in persons with mild AD -The effect of mild AD on short-term memory

-The effect of mild AD on long-term memory
<u>1.3) Reported ‘additional’ cognitive changes in persons with mild AD:</u>
-Persons with AD have the tendency to create their own world
-Limitations in executive functioning of persons with mild AD
-Increasing disorientation of persons with mild AD
<u>1.4) Reported communication changes in persons with mild AD:</u>
-Reported changes in expressive language occurring in persons with mild AD
-Reported comprehension changes in persons with mild AD
-Reported speech motor changes in persons with mild AD
<u>1.5) Reported emotional and personality changes in persons with mild AD:</u>
-Persons with mild AD tend to be perceived as assuming more child-like characteristics and behaviours
-Persons with mild AD tend to become more aggressive
-Persons with mild AD want to initially remain independent
-Persons with mild AD tend to become more depressed

1.1) Reported challenges relating to the motor abilities of persons with mild AD

As previously discussed, there are contradictory findings in the research literature, regarding the motor functioning of persons with AD. It is unclear if motor functions tend to deteriorate or remain comparable with those of the healthy senior control groups (Alzheimer’s Disease International, 2009; Brookshire, 2007; Eslinger & Damasio, 1986; Pettersson et al., 2005; World Alzheimer’s report, 2009). It is thus not surprising that some of the nurses described the motor ability of persons with mild AD as functional whereas others reported motor changes. This will be discussed under the following headings: 1.1.1) the effect of maintained motor ability but reduced cognitive functioning and 1.1.2) potential motor changes in persons with mild AD, as indicated in the table below.

Table 2-1.1: Summary of the reported challenges relating to the motor abilities of persons with mild AD:

<p><u>1.1.1) The effect of maintained motor ability but reduced cognitive functioning:</u></p> <p>-Consequences of maintained motor abilities but reduced cognitive functioning include:</p> <ul style="list-style-type: none"> -Conflict between residents -Conflict between residents and nurses -An increase in nurses' workload <p>-Solutions include:</p> <ul style="list-style-type: none"> -Medicating persons with mild AD -Restraining persons with mild AD
<p><u>1.1.2) Potential motor changes in persons with mild AD:</u></p> <p>-Example: Increased tone during dressing activities</p>

1.1.1) The effect of maintained motor ability but reduced cognitive functioning.

All nurses, who described the motor abilities of persons with mild AD as functional also reported on the challenges arising for patients and their environment. The challenges are a result of identified reduced cognitive functioning of persons with mild AD, as evident in the examples below:

N5: Somtyds nou sit jy vir hulle in die bed. Nou klim hulle uit hulle bed uit. Dan klim iemand anders in. Nou daai resident (sonder AD) verstaan nie dat die vrou (met geringe AD) nie reg is of die man (met geringe AD) nie reg is nie. Hulle raak kwaad...Baie van hulle (persone met geringe AD) gaan slaan vir hulle (persone sonder AD).

Translated N5: Now, sometimes we put them to bed. Now, they climb out of bed. Then somebody else climbs in. Now, that resident (without AD) can't understand that this woman (with mild AD) isn't right or this man (with mild AD) isn't right. They become angry...Many of them (persons with mild AD) beat them (persons without AD).

N8: Wat vir my nou moeilik is, is wanneer ons vir haar alleen laat, dat sy op haar eie is... Dan is die kas deurmekaar gekrap en ons moet (dit) nou weer gaan oordoen... Sy skep vir ons werk, wat ons net nou klaar gemaak het...Dit maak vir my 'n bietjie frustrerend.

Translated N8: What is difficult for me now, is when we leave her alone, that she is by herself... Then the cupboard is pulled messy and now we must redo (it) again... She

creates more work for us, which we just finished. That makes me a bit frustrated.

N6: Now, if you wash this one.... Now if you wash that one, the other one is just gonna go out. Now she didn't even put on the clothes or the gown.

By means of the above examples, it becomes evident that nurses experienced patients' maintained mobility but deteriorated cognitive function as challenging, resulting in fights between residents, when a person with AD climbs into someone else's bed. It can also cause conflict between residents and nurses, when residents' behaviours are perceived by nurses as adding to their workload. Residents can also place themselves in inappropriate social situations as a result of their cognitive limitations but with maintained motor functionality, as mentioned by N6. Solutions to these challenges were suggested by the nurses 5 and 8 and included the following:

N5: Dan kry jy weer die Alzheimer wat op en af loop, sonder om op te hou...Jy kan maar wat (enige iets) maak, hy loop... **daar is 'n pil wat hulle kry om hulle 'n bietjie rustig te maak.**

Translated N5: Then you get the Alzheimer that walks up and down without stopping...You can do what (anything), he walks...**there is a pill that they get to calm them down a little.**

N8: Toe het ek besluit: Ek **maak maar vir jou vas** hier by jou bed...Ek het die toestemming gekry om vir haar vas te maak. Ek doen dit wanneer ek te besig is om met haar te sit of iewers te gaan met haar.

Translated N8: Then I decided: **I will tie you to your bed**...I got the consent to restrain her. I do it when I am too busy to sit with her or go somewhere with her.

These nurses thus suggested to provide persons with mild AD with medication or alternatively restrain them, to hinder constant motor activity, especially unattended wandering and thereby keeping the patients safe. Using medication or restrain would be an indication of ethical and moral patient violations, but the extent and components of this concern are beyond the scope of this study. The above examples illustrate that these nurses observed no motor deterioration but were challenged by the consequences of maintained motor functioning and reduced cognitive functioning, during the mild stage of AD. Maintained motor functioning during the mild stages of AD was discussed in a substantial amount of literature (Alzheimer's Disease International, 2009; Brookshire, 2007; Pettersson et al., 2005; World Alzheimer's report, 2009). This stands in direct contrast to the observations of nurse 2 and 12, as will be discussed below.

1.1.2) Potential motor changes in persons with mild AD.

N2: Dis net party van (hulle) arms en bene is stokstyf gespanne of getrek. Jy kan nie vir hulle uittrek nie of aantrek nie... Ek weet nie hoekom doen hulle dit nie. Vir my lyk dit so, hulle het 'n vrees van val.

Translated N2: It's just that some of (their) arms and legs are very contracted and tense. You can't undress or dress them...I don't know why they do that. To me it looks like, they have a fear of falling.

N12: Sê nou in die begin stadium, as hulle nie meer die ding kan doen nie wat hulle gewoond was te doen... Want “ek kon al die tyd-, **kon ek my skoene self aangetrek** het. Ek kon al die tyd **my knope reg vasgemaak** het. Ek kon al die tyd **die zippie hier (in sy gat) ingedruk** het. Ek kan nie (meer nie).”

Translated N12: Now say in the beginning stage, if they can't do the thing anymore that they used to do... Because “I could always-, **I was able to put on my shoes**. I could always **close the buttons correctly**. I always could **press the zip here (into its hole)**. I can't (anymore).”

Even though nurses 2 and 12 observed changes in motor activity, it is not clear whether these changes can be related to only motor deterioration. It might be possible that motor deterioration is a contributing factor in the above-mentioned examples, even though motor deterioration is mostly described as a symptom merely occurring during the moderate to severe stages of AD (Alzheimer's Disease International, 2009; Brookshire, 2007; Pettersson et al., 2005; World Alzheimer's report, 2009). It is also unlikely that cognitive limitations could account for these motor difficulties. Taking into account the nurses' scenarios, it becomes evident that only procedural routines were mentioned, which are completed by the procedural memory. Deficits related to the procedural memory are however described as symptoms occurring during the later stages of the condition (Zanetti et al., 2001), which provides reason to doubt that cognitive deficits caused patients' difficulties completing the mentioned motor activities. Consequently, the above perceived motor changes can probably be best explained as a result of perceptual changes during mild AD. Previously, it was mentioned that persons with mild AD might present with perceptual changes (Kavcic & Duffy, 2003; Lavenue & Pasquier, 2004; Maddox & Maddox, 2006; Rizzola et al., 2000) which include alterations in “spatial contrast sensitivity, colour, stereopsis, temporal resolution and motion” (Rizzola et al., 2000, p. 1157). Additionally, these patients might present with spatial memory deficits (MacDonald et al., 2001). These alterations manifest in difficulties with object identification and localization as well as route

identification. This could explain nurse 12's observation that patients might struggle to tie their shoes and/or close their buttons or zip, as they cannot adequately locate the hands, shoes, buttons and/or zips in space. Patients might also tense their muscles due to their compromised spatial perceptions. Thus, as nurse 2 stated, increased tone might be due to a fear of falling, as they struggle to estimate the distances and heights in their surroundings. The observations by nurses 2 and 12 could easily be interpreted as changes in patients' motor ability during mild AD, whilst actually perceptual changes might be reported on. Consequently, the observations of all nurses might seem contradicting but when evaluated and discussed in terms of perceptual changes, it is likely that a consensus, rejecting motor deterioration during the mild stage of the condition, can be reached between all nurses.

Nevertheless, according to the nurses' perceptions, motor deterioration becomes more evident during the moderate to severe stage of the condition, as seen below:

N5: "Want hulle staan op hulle stoele uit en hulle kan hulle seer val, want hulle is nie stabiel genoeg nie, somtyds te loop nie."

Translated N5: "Because they get up out of their chairs and they can fall and hurt themselves because they aren't stable enough to walk sometimes."

N5: (Hulle) kan self nie dink om te eet nie. Dan begin jy hulle voer want hulle kan nou nie self dink en sê nie: "Haai lepel of vurk moet nou mond toe kom nie"... Dan staar hulle in die kos.

Translated N5: (They) can't think for themselves to eat. Then you begin to feed them because now they can't think for themselves and say: "Hey, now (the) spoon or fork must come to the mouth" ... Then they stare into the food.

By means of the two examples it is evident that the nurses perceive motor deterioration to occur during the moderate to severe stages of AD. These observations correlate with the research literature (Alzheimer's Disease International, 2009; Brookshire, 2007; Pettersson et al., 2005; World Alzheimer's report, 2009). During the moderate to severe stage of the condition, patients' inability to feed themselves might be explainable by means of a combination of motor, cognitive and perceptual deterioration. Due to patients' overall deterioration, it becomes increasingly challenging for them to complete activities of daily living (Jalbert et al., 2008).

Summary of the reported challenges relating to the motor abilities of persons with mild AD. This discussion was focused around the nurses' perceptions of maintained and/or possible deterioration of motor functions in persons with mild AD. Five nurses spoke about the

consequences related to maintained motor and reduced cognitive functions. These consequences led to an overall increase of conflict and workload for nurses in homes for the elderly. The nurses perceived these disruptions as frustrating and thus employed strategies like medication or physical restraint, to reduce patients' mobility and activity. Nurses 2 and 12 provided examples in which motor activities were compromised. However, these examples were potentially not illustrative of motor deterioration but rather perceptual changes in persons with mild AD.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It is of interest to the SLT to determine the perceptions of nurses regarding the motor functions of persons with mild AD and the challenges thereof. The interview revealed the nurses' needs to reduce patients' motor activities, by restraining and medicating these patients. Restraining or medicating persons with mild AD should not be the prevalent solution to reducing conflict and workload in these homes for the elderly. This might have a negative impact on the well-being of persons with mild AD and might reduce their quality of life. Solutions should be focused on improving communication with these patients, to eliminate conflict and workload in these homes. This suggestion is in accordance with McCallion et al. (1999), also promoting communication as optimal solution, thereby reducing the use of medication and restraints. SLTs can assist nurses in improving their communication with persons with AD, by providing facilitating communicative strategies. Additionally, the SLT can provide nurses with strategies for cognitive stimulation, thereby enhancing or maintaining patients' cognitive functioning and simultaneously reducing or maintaining the challenges related to cognitive deficits in presence of motor functioning.

1.2) Reported Memory Changes in Persons with Mild AD

All of the interviewed nurses identified memory changes in persons with mild AD. As indicated in the table below, these will be reported on in the following order: 1.2.1) general description of memory in persons with mild AD, 1.2.2) the effect of mild AD on short-term memory and 1.2.3) the effect of mild AD on long-term memory.

Table 2-1.2: Summary of the reported memory changes in persons with mild AD:

<u>1.2.1) General description of memory in persons with mild AD:</u> -Memory as earliest symptom -Memory changes <i>across</i> persons with mild AD -Memory changes <i>within</i> individual persons with mild AD -Potential effect of the time of the day on the resultant memory difficulties
<u>1.2.2) The effect of mild AD on short-term memory:</u> -The rate of forgetting information -Denial of short-term memory deficits -Consequences of short-term memory deficits: -Nurses accused of stealing or lying -Aggression towards nurses and residents -Nurses reactions towards patients' accusations and aggression -Benefits of short-term memory deficits (using it to complete activities of daily living)
<u>1.2.3) The effect of mild AD on long-term memory:</u> -Maintained long-term memory -Reference to past experiences as if they occurred in the present

1.2.1) General description of memory in persons with mild AD. Eleven nurses stated that the first symptom, which could be indicative of a potential AD diagnosis, is patients' increasing forgetfulness. Revisiting the previous definition of AD: "a progressive, fatal neurodegenerative condition characterized by deterioration in cognition and memory, progressive impairment in the ability to carry out activities of daily living, and a number of neuropsychiatric symptoms" (Jalbert et al., 2008, p.15). It becomes evident that memory deficits are by definition one of the earliest symptoms of AD.

The nurses discussed patients' forgetfulness as follows:

N5: "As mense begin met Alzheimer's, dan begin hulle vergeetagtig te raak ..."

Translated N5: "If people begin with Alzheimer's, then they begin with becoming more forgetful..."

Nurses 4 and 12 explained what patients forget:

N4: “As ek sien 'n pasiënt is vergeetagtig. Hy vergeet die **datum**. Hy vergeet die **dag**. Hy vergeet **jou naam**... Dit is outomaties, dit is jou Alzheimer’s pasiënt.”

Translated N4: “If I see a patient is forgetful. He forgets the **date**. He forgets the **day**. He forgets **your name**... This is automatically, this is your Alzheimer’s patient.”

N12: “Sy begin sommer haar goed weggee. Dan vergeet sy nou vir wie het sy dit nou gegee.”

Translated N12: “She will just give her stuff away. Then she will forget now, who she gave it to.”

The finding that eleven nurses considered forgetfulness as the first symptom of mild AD, stands in direct contrast with Werner (2003). She found that caregivers, specifically family members, often disregarded the memory loss as being part of old-age, which led to a delay of an AD diagnosis. The nurse participants might be more knowledgeable about the symptoms of AD compared to caregivers, due to their general medical training. Furthermore, they might be more aware of forgetfulness as a symptom of AD, due to the disclosure of patients’ diagnosis at admission to the homes. Nurse 9 explicitly stated that when patients are admitted, the nurses are part of their admission and/or need to revisit patients’ files and inform themselves about patients’ diagnosis prior to caring for and treating them. This might explain the discrepancy between the findings of Werner’s (2003) and the current study. In this study, it was favourable to realise that nine nurses discussed forgetfulness as first core symptom of AD. Thus, their perception of the core symptom correlates with the core symptom mentioned by Martin et al. (1985). They state: “Indeed, memory dysfunction is more frequently cited as the earliest clinical symptom in AD and is considered one of the primary diagnostic criteria” (Martin et al., 1985, p.323).

Although forgetfulness seems to be a strong early indicator of AD for the nurses, it was mentioned by six nurses that memory deficits vary *across* patients and can change *within* individual patients. Nurse 2 summarised the difference in memory deficits *across* patients as follows:

N2: “Ek kan vandag nou met hierdie ene gesels...: ‘Ek gaan môre jou hare kom was.’ ‘Nee, okay is fine.’ **Dan party van hulle onthou nog** ek het gesê, ek gaan môre naels kom sny of hare was, **maar die anders vergeet** dit nou weer. Daar is party wat sou sê: ‘Nee, het nurse so gesê? Nee, nurse ek weet nie maar laat ons maar so maak’”.

Translated N2: Now today I can speak to this one...: “I will come wash your hair tomorrow.” “No, okay that is fine.” **Then some of them remember** I said, I will come

cut nails or wash hair, **but now others will forget** it again. There are some that would say: “No, did nurse say that? No, nurse I don’t know but okay let’s do that.”

Nurse 5 also stated the following, with regards to the memory changes *across* patients:

N5: “En elke pasiënt verskil. Almal het nie dieselfde uitdeling van Alzheimer’s nie.”

Translated N5: “And every patient differs. Not everyone has the same distribution of Alzheimer’s.”

Nurse 2 and 6 provided examples to illustrate the change in memory *within* an individual patient:

N2: Maar **dan onthou hulle goed**, party van hulle. A., sy kan so mooi onthou. Dan sê sy: “Nurse, bel my seun.” **Dan sê sy daai nommer presies** ... As ek nou weer vra: “Wanneer gaan ons vir S. bel?”... Nou sal sy kyk: “Het jy al vir S. gebel? Ken jy sy nommer?” **Dan vergeet sy. Dan sê ek vir haar die nommer.**

Translated N2: But then **they remember well**, some of them. A., she can remember so nicely. Then she says: “Nurse, phone my son.” **Then she gives that number precisely**... Now when I ask again: “When will we call S. again?” ... Now she will look at me: “Have you called S. already? Do you know his number?” **Then she forgot. Then I give her the number.**

N6: That mama, **in the mornings** she can sing so nice...And then you ask: “Oh, can you please sing for me my hymn?... My hymn is number 269” ... And then we are gonna sing for her...But **during the day, she can't even remember** that song.

By means of the above-mentioned examples, it becomes clear that these nurses observe a change in memory capabilities within individual persons with mild AD over the course of a day. According to nurse 6 the memory functions routinely declined as the day progressed. Nurse 3 discusses the contrary after being asked if patients remember more during certain hours of a day:

N3: Nee, hulle het nie eintlik...'n patroon nie. Vandag is hulle okay en môre (nie)... **Is nie eintlik 'n vaste patroon nie...**Jy kan **nie sê dis ure nie** want somtyds is dit maar **net asof dit net verby gaan dat hy nou vergeet.**

Translated N3: No, they don’t actually have...a pattern. Today they are okay and tomorrow (not)... **There isn’t actually a fixed pattern...** You **can’t say it’s hours** because **sometimes it’s just as if now the forgetting just passes.**

The above quotes firstly illustrate that these nurses perceived a change in memory functions *across* patients. Secondly, nurses’ statements show that memory functioning *within* an

individual person with mild AD might change throughout the day. However, by means of the nurses' experiences, it cannot be concluded that patients' memory consistently and continuously deteriorates as the day progresses (for example at the end of each day). The mentioned memory differences *across* and *within* patients might be clarified through the study conducted by Hart et al. (1988). These researchers hypothesise about memory changes in terms of limited memory capacity available to persons with mild AD. They discuss that recalling information would exhaust memory capacity and would thus lead to patients forgetting other information. They also state that visual stimuli would increase the amount and accuracy of information being recalled, as recall would be based on visual and verbal memory, thereby increasing the efficiency of memory capacity. This means that certain visual stimuli might lead to greater recall of information, as less memory capacity is needed to store verbal information in the presence of visual stimuli. In theory that would mean for nurse 2's example, if the patient would have looked in the mirror whilst the nurse told her that she was going to wash her hair tomorrow, she might have been more likely to recall the nurse's intentions, when seeing the nurse and herself in the mirror the next day. The nurse and she, as patient, would then become the visual stimuli, which might enhance her memory. Even if the patient presents with visual memory deficits, the patient's chances of recalling the nurses' message will not be reduced by nurses consciously referring to a visual stimulus (which might include people, objects or places) under discussion. Contrary, the absence of visual stimuli might reduce the chances of the patient's ability to recall the nurse's intentions (Hart et al., 1988). Taking into account the above discussion, the observed memory differences *across* and *within* individual persons with mild AD could be explained by Hart's et al. theory (1988). According to the nurses' perceptions, these memory differences are most prevalent in patients' short-term memory deficits, as discussed in the following section.

1.2.2) The effect of mild AD on short-term memory. Deficits in short-term memory refers to patients' difficulties learning or remembering novel information (Greeff, 2009). All interviewed nurses perceived persons with mild AD to experience short-term memory deficits. For example, nurse 10 stated the following:

N10: "Meerderheid van ... hulle het ('n) short memory, hulle kan nie daai onthou nie."

Translated N10: "Most of...them have (a) short memory, they cannot remember that."

Some of the nurses also noticed that the rate, in which persons with mild AD forget information, differs. According to four nurses, some patients forget what was said or who visited a few

minutes after a conversation or a visit, whilst others forget hours or a day later. The nurses 2, 5 and 9 provided the following example:

N2: Hulle sal oor en oor dieselfde storie vra... Ek dink nie as jy vandag vir hulle dit sê nie en julle sê dit (storie) môre weer, **hulle verstaan nie, jy het dit (storie) gister vir hulle gesê nie.**

Translated N2: They will ask you the same story over and over again... I don't think that if you tell them this (story) today and tomorrow again, **they understand, you told them that (story) yesterday.**

N5: "Of 'n **paar ure**, dan weet hulle nie wat hulle vir jou gesê het nie."

Translated N5: "Or a **few hours**, then they don't know what they said to you."

N9: "Yes. But she will tell you exactly the same thing over and over. **You can just walk out of the room, come back and she will repeat herself.**"

The observation of these three nurses is consistent with the study by Hart, et al. (1988). These researchers provide an explanation as to why persons with mild AD might forget information as quickly as 10 minutes following its presentation. They state that AD is related to a pattern of deviation in "the subiculum and entorhinal cortex of the medial temporal lobe" (Hart, et al., 1988, p.35), disrupting the connection to the hippocampal formation. The partial disconnection reduces the input and output of information to the hippocampus and might limit its effective storage shortly after learning. (Hart, et al., 1988).

Taking into account the above theory, it becomes apparent that information can be lost due to deficits in memory storage. Another reason for the rapid loss of information might be due to deficits of the working and/or visual memory. Working memory deficits result in patients' difficulties of processing previously stored or incoming information, by means of cognitive resources (Dijkstra et al., 2004). This would mean that persons with AD would have difficulty to process previous events or everyday conversations, explaining why they would forget information within 10 minutes following its presentation. Visual memory deficits influence patients' identification and recall of object and spatial information (Wheeler & Treisman, 2002). This would mean that they might not remember or consciously visualise the objects and/or people in the room, increasing their difficulty to process and understand conversations, as visual stimuli no longer act as triggers to access information stored in the long-term memory. The above provides an explanation for the nurses' experiences, of how deficit in memory storage, working memory and visual memory caused patients to forget the content of conversation as soon as they left the room. This experience might cause nurses to think that persons with AD are only 'going to get worse' anyway (Hopper, 2003, p.345), thus focusing

on the physical care of the patients rather than the cognitive, emotional or communicative care. Nevertheless, the fact that some information can be stored and recalled, provides reason for additional interventions with persons with mild AD.

Interventions are however only possible if patients are not in denial of their memory deficits and are willing to receive help. Nurse 8 discussed the problem of patients in denial, not being ready to admit their memory deficits. These deficits can have an effect on patients' social and emotional lives, as mentioned by some of the nurses. They provided examples of patients' deficits and the consequences thereof:

N3: Hulle ...verplaas hulle goed. Hulle sit hulle klere by verkeerde kamer of so ... En jy as verpleegster moet maar net gaan en dan gaan haal dit en sit dit by die regte plek.

Translated N3: They... misplace their stuff. They put their clothes into a wrong room or such... And you as a nurse must just go and then get it and put it into the right place.

Nurse 5 further elaborates on belongings being displaced:

N5: “Sy beskuldig jou...Sy het die ding daar gesit en dis nou weg. En jy het die nou gevat. En sy glo dit is so.”

Translated N5: “She accuses you...She put the thing there and now it's gone. And now you took it. And she believes it is like that.”

Following from what the nurses 3 and 5 said, it becomes evident that challenges arise if persons with mild AD start to accuse the nurses of stealing their belongings. Due to patients' strong belief that their things must be stolen, patients go through emotional turmoil and can easily isolate themselves socially. The nurses might also feel challenged to provide the best care to these patients when continuously accused of stealing.

Further the nurses are regularly accused of lying, as described by nurse 5:

N5: Kyk die een resident...sê dat hulle gesê het, haar kind was hier gewees. Nou sy kan nie onthou nie haar kind was hier nie, maar die kind was regtig waar hier. En dit was seker nog in die week of die dag voor dit wat die kind hier was. Maar sy sê vir my: “Hulle sê die kind was hier. Ek het nie die kind gesien nie. Hoekom jok hulle vir my?”

Translated N5: Look the one resident... said that they told her that her child was here. Now she cannot remember her child was here, but the child was really here. And it was surely within the week or the day before that the child was here. But she says to me: “They say the child was here. I didn't see the child. Why are they lying to me?”

The nurses being accused of lying might impact the quality of care in the same way that accusations of stealing do. Shigenobu et al. (2002) found that these accusations have a negative impact on the relationships between caregivers, including nurses, and the persons with AD. Nurses regularly develop negative attitudes towards the persons with AD, due to their behaviours. These are considered as care obstacles, influencing the quality of care and reducing nurses' job satisfaction (Moyle et al., 2011). Accusations also put more mental strain on caregivers, including nurses, thus reducing their mental well-being and increasing the challenges related to the care of persons with mild AD (Shigenobu et al., 2002).

The nurses experienced care as even more challenging when aggressive behaviour increased, in the majority of persons with AD. The aggression seemed to be directed towards the nurses and other residents, as apparent by the nurses' observations below:

N3: Hulle vergeet. Nou het hulle ... miskien nog nie gewas nie. Nou sê jy: "Kom ons gaan bad." Dan sê hy: "Ek het klaar gebad" en dan is dit eintlik 'n heelwat van 'n gesukkel, om hulle by die bad te kry en daai, want in sy mind het hy nou klaar gewas. "Hoekom moet ek nou weer was?! (HIERDIE UITING WAS IN 'N BAKLEIERIGE EN AGGRESSIEWE STEM GEMAAK.)"

Translated N3: They forget. Now, maybe they... haven't been washed yet. Now you say: "Come, let us bath." Then he says: "I bathed already" and then it is actually a big struggle, to get them to the bath and such, because in their mind they are done bathing. "Now, why must I bath again?! (THIS STATEMENT WAS SAID WITH A FIGHTING AND AGGRESSIVE VOICE.)"

The above example illustrates the aggression and struggle directed towards the nurses. Nurse 5 describes the aggression towards other residents:

N5: Somtyds nou sit jy vir hulle in die bed. Nou klim hulle uit hulle bed uit. Dan klim iemand anders in. Nou daai resident (sonder AD) verstaan nie dat die vrou (met geringe AD) nie reg is of die man (met geringe AD) nie reg is nie. Hulle raak kwaad... Baie van hulle (persone met geringe AD) gaan **slaan** vir hulle (persone sonder AD)... Ja, hulle klim sommer in die kooi in en dan sê hulle: Dis hulle kooi daai... Hulle jaag mekaar dan uit. "Dis my kooi daai!"

Translated N5: Now, sometimes we put them to bed. Now, they climb out of bed. Then somebody else climbs in. Now, that resident (without AD) can't understand that this woman (with mild AD) isn't right or this man (with mild AD) isn't right. They become angry... Many of them (persons with mild AD) **beat** them (persons without AD) ... Yes,

they just climb into the bed and then they say: This is their bed... They chase each other out. "This is my bed!"

Nurse 5 concluded the statement above by saying: "Dis alles dinge waar ons oë en ore moet wees. En dis moeilik soms om orals te wees."

Translated N5: "These are all things where our eyes and ears need to be. And it is sometimes difficult to be everywhere."

All the nurses discussed the challenges that arise in relation to increasing aggressive behaviours of persons with mild AD. Four nurses made statements similar to that of nurse 5, saying that it is at times impossible to continuously watch persons with AD. However, if aggressive behaviours are thought of as an expression of unmet desires and needs of patients (Penrod et al., 2007), the solution would be to find ways to meet patients' desires. This theory would explain why aggressive behaviour increases as the condition progresses. As will be discussed below, nurses observed that patients' communicative functions deteriorate throughout the course of the condition. Patients' limited capability to verbalise their needs might lead to fewer of it being met, which would then result in increasing aggression in persons with AD, as experienced by the nurses. It could therefore be beneficial, for the nurses, to establish the source of patients' aggressive behaviours.

However, an increase in aggression can also cause fear, anxiety and stress in nurses, often resulting in emotional turmoil and reduced job satisfaction (Brodaty et al., 2003; Edberg et al., 2008; Grant et al., 1996). Emotional turmoil can easily lead to feelings of being overwhelmed, thereby reducing nurses' emotional availability to the patients as they struggle to cope with their own emotions. Emotional turmoil and reduced job satisfaction can thus lead to poorer quality of care. This would mean that even though it might be beneficial for nurses to establish the source of patients' aggression, they might fail to do so because of their lack of job satisfaction or own emotional challenges, making it more difficult for them to emotionally care for the persons with AD. The nurses described their reactions, of regularly being victimised by persons with AD, as follows:

N2: "Dit maak **mens moeg**."

Translated N2: "It makes **you tired**."

N5: "As ek hier weg ry, **jou brein is moeg**!"

Translated N5: "If I drive away from here, **your brain is tired**!"

N6: "... we try to help them. But it is **difficult**. It is very difficult."

N8: “Dit is **harde werk**.”

Translated N8: “It is **hard work**.”

These findings correlate with research conducted by Edberg et al. (2008). These authors also found that nurses might struggle to cope with the challenges experienced when caring for persons with AD. They similarly discuss nurses’ difficulty to act in the best interest of the patients even though they might be resistant or become aggressive towards the nurses, due to not understanding or forgetting the intentions behind proposed activities (e.g. personal hygiene).

By means of the above, it becomes evident that nurses experienced patients’ short-term memory difficulties to provide great challenges to the care of AD. Four nurses however, also admitted ‘using’ patients’ short-term memory problems to comfort the patients and complete their physical care, as apparent in the following quote:

N9: Mrs A. she is a very stubborn lady. The carers will go to her and ask: “Mrs A. please get up, we want to wash you.” Then she will say: “No, I am not gonna do it!” Then they tell me and I go back to her and I say: “Mrs A. come now. You must get up.” She will totally forget that she told there, just 5 minutes ago, to the carers that she don't wanna bath. But then she will get up by me.

According to nurse 9, different carers or nurses can therefore approach the patient soon after one another and achieve the desired response and complete the physical care of the patient. Due to the patient’s short-term memory difficulties, various carers or nurses might get different responses from the patient within a short period of time, thus making it easier to complete the physical care of these patients. Furthermore nurse 7 and 8 explain:

N7: Nou as dit kom by bad, as jy miskien die naels moet doen en sulke tipe goeds, jy moet vir hulle baie gemaklik maak...Die een oumatjie, sy gaan nie was voor jy nie vir haar gesê het: “Maar jou seun kom vandag 'n bietjie-.” **Jy moet so bietjie 'n leuentjie waag, net om vir hulle te kan rustig voel.**

Translated N7: Now if it comes to bathing, if you maybe must do the nails and such type of things, you must make them very comfortable... The one little granny, she will not wash before you said to her: “But your son will come for a little bit today.” **You need to dare a little lie just so they can feel calmly.**

N8: Dan sê ek: “Kom klim gou in die kar (praat van rolstoel)”...Dan sê ek: “Kom ons gaan gou vir oom S. kuier. Dan klim in die kar. Dan stoot ons vir u na oom S. toe.” So dan klim sy in die kar. Dan maak ons liggies vir haar vas en dan sit sy by ons. Dan het

sy weer vergeet, sy wou nou iewers heen gaan.

Translated N8: Then I say: “Come, quickly climb into the car (referring to wheelchair)”.

Then I say: “Come, we quickly visit uncle S. Then climb into the car. Then I will push you to uncle S.”. So, then she climbs into the car. Then we lightly strap her in and then she sits with us. Then she already forgot, she wanted to go somewhere.

In both cases these nurses would ‘use’ deceit and patients’ short-term memory problems to their advantage, the main reason being to complete physical care of all patients. Using deceit would be an indication of ethical concern, but the extent and components of this concern are beyond the scope of this study. Patients’ short-term memory was thus also perceived as beneficial by four nurses. From the above discussion, it becomes evident that the majority of the nurses have highlighted the challenges they face as a result of the short-term memory problems experienced by persons with mild AD as well as how it can be used to aid the care they have to provide.

Interestingly, the nurses reported that even though deficits in short-term memory were present, persons with mild AD continued to remember their routine activities, like eating and taking tablets. They would however forget that they have completed these routine tasks shortly after having done it, as evident by means of the following quotes:

N7: Hulle kom vir medikasie. Gaan sy pilletjie kry en na 'n tydjie, so half uur later gaan hy terug kom en sê: Hy het nog nie medikasie gekry nie. “Kan suster my medikasie vir my gee?”

Translated N7: They come for medication. Get his pill and after a short time, like half an hour later, he will come back and say: He hasn’t gotten his medication yet. “Can sister give me my medication?”

N12: “Sy vergeet. Sy sal vir die mense sê: Ek het haar nog nooit vandag kos gegee nie. Maar ek weet mos, ek het vanoggend al (kos vir haar gegee).”

Translated N12: “She forgets. She will say to the people: I never gave her food today. But I know, I have (given her food) already, this morning.”

Taking into account the above examples provided by the nurses, it seems like the routine has been stored in the long-term procedural memory of these patients. Due to the remaining procedural memory function in the early stages of the condition, persons with mild AD might remember the routine but forget their execution of it, as the execution might have not been stored in the short-term memory. Considering the examples by nurses 7 and 12, the routines would be eating and drinking the medication, which patients would have performed multiple

times throughout their lives and hence these routines might be stored in their long-term procedural memory. Remembering the momentary execution of these activities would require the short-term memory to be able to process, store and retrieve this information. As discussed previously, this might be challenging due to working memory deficits and/or the partial disconnection of the hippocampus. The working memory might limit the patient's ability to process new information (Dijkstraa et al., 2004), whereas a partial disconnection to the hippocampus might hinder effective storage shortly after learning (Hart, et al., 1988).

According to the nurses, persons with AD might not be able to remember basic procedural routines, during the moderate and severe stages of the condition, as seen below:

N6: "Where are you going mamma?" "I am going to the toilet." Okay, then at the toilet she is just gonna stand. Now you must...take it off their pants... And then: "Pee mama." Now, then she is gonna pee. Only they might have forgot... Now always you must remind.

In conclusion, all nurses stated that persons with mild AD present with varying degrees of short-term memory deficits. The short-term memory deficits can be used to the nurses' advantage but can also can result in many challenges in caring for persons with mild AD. Contrary to the short-term memory, nurses perceived long-term memory functions as mostly being maintained in persons with mild AD, as discussed below.

1.2.3) The effect of mild AD on long-term memory. Long-term memory includes the declarative, autobiographical and procedural memory, with the declarative and autobiographical memory comprising of the semantic and episodic memory. The semantic memory describes the vocabulary and stored knowledge acquired through books, education and experiences. This information is of factual nature and can be recalled throughout life (Tulving, 1983 as cited in Dijkstraa et al., 2004). The episodic memory stores information and experiences of personal relevance (Haj et al., 2015). The nurses experienced that the long-term memory of persons with AD would remain unchanged until the later stages of the condition:

N1: "He got a long-term memory."

N3: "Hulle onthou beter wat in die verlede gebeur het."

Translated N3: "They remember better what happened in the past."

Considering the fact that the content of conversations with persons with mild AD are increasingly focused around past experiences, shows that their long-term episodic memory remains unchanged within the mild stage of the condition. The experiences of these nurses are

comparable to the findings by Greeff (2009). He also states that in the mild stage of the condition patients' short-term memory is affected but their long-term memory remains unchanged. The nurses and Greeff (2009) might have defined long-term memory only in terms of the episodic memory which is expected to be preserved for longer periods of time (Haj et al., 2015), compared to the semantic memory which might already be affected during the mild stage of the condition Tulving, 1983 as cited in Dijkstra et al., 2004).

Eight nurses further elaborated and indicated that persons with mild AD might not only recall past experiences more easily, but they tend to speak about the past as if it were the present. Some nurses described it as follows:

N10: "... hulle lewe weer meer (in) hulle verlede, op die huidige oomblik."

Translated N10: "...they live more (in) their past again, in this present moment."

N5: "Want jy kan sien, dit is hoe hulle somtyds lewe in hulle kinderjare."

Translated N5: "Because you can see, that is how they sometimes live in their childhood."

Interestingly, nurse 9 working on night-shift also stated:

N9: They get nightmares... They will talk about things that happened in the past... But it's every night the same thing... "Go play outside!" "Don't come in my house!" ... Tomorrow it's: "Why are you standing here?" "Get out of my house!" Then we will ask: "Who are you talking to?" "Don't you see that children!" "I am so fed up with those children!" "They play every time in the house." And then I will tell the day staff. The day staff will enquire with the daughter. The daughter will say: "No she didn't like that children must play in the house. She will always tell the children: "Get out of the house!" ... Because she is living in the past.

Taking into consideration nurse 9's experiences, it would seem that these patients would tend to recall personal information from the past rather than the present. Nurse 9 explained their ability to recall the past experiences as follows:

N9: What I noticed is they live back, backwards. Something that might be wrong or something they can't deal with, maybe didn't deal with in the past. Can be with a divorce or something and...now only it comes forward and...for them it's like it's happening now.

There seems to be increasing evidence that information of personal relevance, acquired earlier in life (e.g. childhood or early adulthood), is stored in the episodic memory, becoming more strongly consolidated and integrated within the brain (Haj et al., 2015). Because of its greater

integration into the brain, this information remains more accessible to patients during the mild stage of AD, which would explain the nurses' observations.

The recall of forgotten personal information can be enhanced by means of visual stimuli, as observed by nurse 12:

N12: En dan sal sy sê, as jy verby stap: “Weet jy ons het ook so ene (’n televisie) gehad daar by die huis op die plaas” ... “Ek sou nou buite gesit het (op die plaas).” As jy sien daai excitement kom nou weer op... Jy het nou iets getrigger.

Translated N12: And then she will say, when you walk past: “You know, we also had one of those (a television) in the house, there, on the farm” ... “Now I would have sat outside (on the farm).” Now, if you see this excitement comes up again... You just triggered something now.

Nurse 12's observation is coherent with literature. Similar to Hart et al. (1988), Ally (2012) describes enhanced recall, by means of verbal and visual cues, in terms of the dual-coding. It is suggested that a visual stimulus evokes an image and a verbal code. These two representations are stored in the memory of persons with mild AD. By providing a visual and verbal stimulus both representations are activated thus increasing the likelihood of successful recall. In the above example, provided by nurse 12, the television evoked the visual representation of having had such a television on the farm. Even though the patient possibly presented with visual memory deficits, she clearly and consciously acknowledged and processed the television as visual cue and was able to recall her prior experiences related to the television. By means of additional verbal cues, the nurse was able to request more information about the patient's farm life. The patient's recall was triggered by the television and due to the strong associations to the farm, the nurse was able to successfully prompt for more information regarding the patient's farming experiences.

However, as the condition progresses, some of the nurses observed that the long-term episodic memory becomes more affected and even the strongly integrated personal experiences of patients might be forgotten even in the presence of visual stimuli, as evident below:

N3: “Hulle begin...hulle familie te vergeet.”

Translated N3: “They begin...to forget their family.”

N5: “Wil ek sê, is krag as jou eie mense jou nie herken nie. Of jou ma herken jou nie.”

Translated N5: “I want to say, it has power if your own people don’t recognise you. Or your own mom doesn’t recognise you.”

Summary of the reported memory changes in persons with mild AD. All the nurses perceived persons with mild AD to presented with short-term memory deficits. Memory was discussed as earliest observed symptom of AD by eleven nurses. Although memory deficits were perceived as prevalent within the mild stage of the condition, six nurses seemed to observe memory changes across and within individual persons with mild AD. These memory changes were not associated with specific times of the day (e.g. morning, afternoon or evening). Additionally, four nurses reported that the rate, at which persons with mild AD would forget new information, varied. Due to the increasing forgetfulness, persons with mild AD would regularly accuse nurses of stealing or lying, when in fact they misplaced their belongings or forgot information. The nurses also stated that the patients’ forgetfulness would result in increasing aggression towards them and residents and yet multiple persons with mild AD were in denial of their short-term memory deficits. Even though the nurses felt very challenged by these patient’ behaviours, four of them used the patients’ short-term memory deficits to their advantage as a means to complete activities of daily living.

Almost all the nurses mentioned that the long-term memory of persons with mild AD is maintained. The majority of patients seemed to primarily speak about personal experiences from their past. According to the nurses, some patients not only spoke about their past experiences but referred to them as if these experiences were occurring in the present.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It was of significance for the SLT to establish how the nurses evaluated the memory of persons with mild AD. These findings illustrate that the nurses mostly perceived patients’ memory deficits as challenging. These challenges increased the stress experienced by nurses. To reduce this stress, it would be beneficial to assist patients with their memory deficits. According to the American Speech, Language and Hearing Association (2016), a SLT can assist persons with mild AD with memory strategies, like written cues or memory books. Such strategies could support persons with mild AD in their recall of personal or factual information. In the South African governmental homes for the elderly, the SLT could assume the role of training nurses in the application of these memory

strategies, thereby assisting the patients and potentially reducing the stress experienced by nurses.

1.3) Reported ‘Additional’ Cognitive Changes in Persons with Mild AD

The other cognitive changes identified by the nurses will be discussed in terms of 1.3.1) persons with AD have the tendency to create their own world, 1.3.2) limitations in executive functioning of persons with mild AD and 1.3.3) increasing disorientation in persons with mild AD, as apparent by the table below.

Table 2-1.3: Summary of the reported ‘additional’ cognitive changes in persons with mild AD:

<p><u>1.3.1) Persons with AD have the tendency to create their own world:</u></p> <ul style="list-style-type: none"> -Examples of patients creating their own worlds -Patients’ creation of own worlds can result in accusations towards nurses
<p><u>1.3.2) Limitations in executive functioning of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Example showing reduced cognitive flexibility and reasoning -Impact of attention on reasoning and problem-solving -Need for assistance by nurses (by means of conversations and providing options) -Daily variability in executive performance by persons with mild AD and potential reasons -The awareness of deficits by persons with mild AD and the consequences thereof
<p><u>1.3.3) Increasing disorientation of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Increasing environmental disorientation following the admission to the homes for the elderly -Example of disorientation when environmental changes occur -Solution to environmental changes -Increasing disorientation in time

1.3.1) Persons with AD have the tendency to create their own world. According to five nurses, persons with mild AD might lose themselves in their imagination and create their own world. Nurse 1 described it as follows:

N1: “They just have **their own world...** They **imagine things...** That are not there at all. Things that are not happening.”

The nurses 5 and 12 provide examples below, of persons with mild AD who created their own worlds, apparent by their continuous retell of the same fictional story, which they truly believed to be true:

N5: Hy sê: “Hy het net hier verby gestap. Toe sien hy die klomp mense...en toe kom hy in” ...But in the meantime (N5 HET KODEWISSELING GEBRUIK), het sy kinders hom in gebring...Dis dan wat hy nou daar dink, hy het hier verby geloop (en) toe sien hy: Jis, die mense sit lekker... Hy wil ook...sit by hulle.

Translated N5: He says: “He just walked past here. Then he saw a lot of people...and then he came inside” ...But in the meantime (N5 USED CODE-SWITCHING), his children brought him in...Now, that is what he’s thinking there, he walked past here (and) then he saw: Gee, the people sit...happily. He also wants to...sit with them.

N12: Jy vra: “Haai, het mevrou D. dit (blomme) hier gesit? Dit lyk mooi.” “Nee, my kind of my die of my dit het nou dit daar neer gesit.” Maar ek weet, hulle was nie daar nie.

Translated N12: You ask: “Hey, did madam D. put this (flowers) here? It looks beautiful.” “No, my child or my this or my that put it there now.” But I know, they weren’t there.

The nurses 6 and 7 also elaborated on persons with mild AD creating their own world by claiming objects of other patients to be their own. Nurse 6 for example said:

N6: Sometimes...she put on the jersey...the jersey is the same like that one. She is gonna say: “No, no this is my jersey” and then they want to fight... “This is my jersey!” And you say: “No, this is not your jersey.”

The nurses seem to have observed that persons with mild AD might struggle to comprehend that other patients might have belongings similar to theirs. The fact that they would fight with each other, shows that they are not merely confused about their possessions, but they truly believe that someone took their belongings. Their thoughts become their reality even in the mild stage of the condition. The nurses experienced that throughout the course of AD, this phenomenon intensifies up to the point where patients merely live in their own world. This can result in false beliefs and accusations towards nurses as evident below:

N12: “**As jy vir hulle wil was, dan dink hulle jy wil vir hulle seer maak.** Dan skreeu hulle: “Eina! Los my!””

Translated N12: “**If you want to wash them, then they think you want to hurt them.** Then they shout: “Ouch! Leave me!””

N5: En hulle (familielede van persone met AD) glo ook as hulle ma gesê het, ons (verpleegsters) het hulle nou geslaan by voorbeeld. Dan glo daai kinders (dit) maar hulle verstaan nie dit is part van Alzheimer's nie. Dat hulle (familielede van persone met AD) nie eintlik weet waarvan hulle praat nie.

Translated N5: And they (family members of persons with AD) also believe if their mom said, now we (nurses) hit them for example. Then these children believe (this) but they don't understand that its part of Alzheimer's. That they (family members of persons with AD) don't actually know what they speak about.

By means of the above examples, it becomes evident that some of the nurses observed how persons with mild AD might create their own realities and share these with their family. They might truly believe that the nurses wanted to cause harm or became harmful towards them, even if the nurses merely washed these patients. As nurse 5 stated, the families might assume the patients' stories to be true, consequently accusing the nurses of aggressive behaviour towards these patients. In order to cope with the accusations, the nurses need to be constantly reminded that these patients have created their own reality. The creation of their own reality, as observed by some of the nurses, might be the result of increasing cognitive deterioration (Dijkstra et al., 2004; Greeff, 2009; MacDonald et al., 2001; Maddox & Maddox, 2006; Ostwald et al., 2002). Decreasing memory abilities and reasoning skills influence patients' thinking processes, resulting in their creation of their own realities. Due to their difficulty to perceive reality, they tend to base judgements on preconceived notions, acquired throughout their life, thus showing cognitive inflexibility. The extent in which cognitive flexibility, reasoning and other executive functions are affected in persons with mild AD will become apparent, by taking into account the nurses' statements, in the following section.

1.3.2) Limitations in executive functioning of persons with mild AD. The nurses' perceived that persons with mild AD would present with limitations related to cognitive skills, resulting in a loss of executive functioning, including decreasing cognitive flexibility, attention, reasoning and problem-solving skills. All executive functions are linked to one another and will thus be discussed collectively. Nurse 7 identified patients' limitations with regards to their executive functioning in the following scenario:

N7: As die seun inkom en jy **groet die seun**. Nou gaat daar 'n nurse verbykom, 'n vroumens nurse en die nurse gaan nou sê: “**Dis mos my boyfriend** wat nou hier verbykom.” Dan gaan ouma nou stop en **vir jou slaan**: “Jy gaan nie aan my seun raak nie”... Dis die gouste (manier) wat jy **vir hulle moeilik maak**... “**My seun is my seun**

en jy gaan hom nie kry nie. Ek sal self sorg dat hy 'n regte vrou kry.”

Translated N7: If the son comes in and you **greet the son**. Now a nurse will walk past, a female nurse and now the nurse will say: “**This is my boyfriend**, who is walking past.” Then the granny will stop and **beat you**: “You won’t touch my son” ... That’s the quickest (way) to **make them difficult**... “**My son is my son and you won’t get him**. I, myself will reassure that he will get the right wife.”

Nurse 7’s perception is in accordance to Brookshire (2007), who states that persons with mild AD struggle to understand figurative language. Figurative language demands higher level language processing and cognitive resources like cognitive flexibility, attention and reasoning, which are functions affected in persons with mild AD (Brookshire, 2007; De Bartolo et al., 2009; Ostwald et al., 2002). As previously mentioned, cognitive flexibility provides individuals with the skill to adapt their thinking to a changing context, thereby permitting individuals to think in various ways (Ostwald et al., 2002). Cognitive flexibility assists with detecting novel information, using working memory, monitoring performance, evaluating and integrating options and/or meanings, inhibiting responses as well as making decisions (De Bartolo et al., 2009). Cognitive flexibility thus permits individuals to think about and analyse statements critically, thereby reasoning about all the available meanings to certain statements. By means of reasoning through and taking into account all meanings possible, individuals will be able to understand humorous statements. However, persons with mild AD present with limitations of executive functioning, which could explain nurse 7’s observation of the patients’ difficulty with comprehending humour.

Another executive function, identified by the nurses, is attention. Nurse 2 indicated that attention could impact the thinking processes of persons with mild AD, as apparent below:

N2: “... maar dan moet jy ook dink vir hulle. Want hulle kan nie meer dink nie. Hulle **dink is nou maar 'n bietjie kort**.”

Translated N2: “...but then you must also think for them. Because they cannot think anymore. Their **thinking is a bit short now**.”

Nurse 2 speaks about patients’ thinking being short. This might mean that patients might not reason, analyse and evaluate all options before making an informed decision. They might easily be distracted by their environment, due to their limited attention span (Langley et al., 1998). The majority of nurses mentioned that patients required assistance in their decision-making and problem-solving process, as evident below:

N7: “Ja, met ’n **gesprek** met ’n nurse sal hulle dit kan oplos... Ons moet **saam met hulle probeer die probleem oplos.**”

Translated N7: “Yes, with a **conversation** with a nurse, they will be able to solve it... We must try **solve the problems together with them.**”

Nurse 7 stated that they would engage persons with mild AD in a conversation in an attempt to solve their problems. They would provide patients with options to solving a problem. No reference was made to the number of options patients would be given. Ideally two options would be used, helping the patient to choose the most appropriate option. By providing options, the nurses assist patients in making an informed decision. They thus support patients with their limitation related to cognitive flexibility and simultaneously provide stimulation thereof.

Interestingly, the nurses observed that persons with mild AD do not necessarily present with difficulties of executive functioning daily, but rather present with variable executive performance. The nurses 2 and 10 specified that executive skills might change *within* an individual patient:

N2: “Jy moet maar vir hulle dink. Hulle kan nie self dink nie, **miskien vandag maar môre dan weer nie.**”

Translated N2: “But you must think for them. They can’t think for themselves, **maybe today but tomorrow not anymore.**”

N10: Somtyds kan hulle vir jou reg help. As ek miskien sê: “Dit is so.” Dan sal hulle somtyds sê: “Nee maar ek het vergeet, dis so.” Dan kan hulle nou vir jou nog reg help.

Translated N10: Sometimes they can help you right. If I maybe say: “It’s like this.” Then they will sometimes say: “No but you forgot, it’s like this.” Then now, they can help you right.

The variable executive functioning perceived by the nurses, could be the result of many factors influencing patients’ reasoning and problem-solving skills. For example, reasoning and problem-solving could be reduced if patients are increasingly distracted, thereby not focusing on the current task. Consequently, by reducing the distractions and increasing patients’ attention on the current task, patients problem-solving and reasoning skills might improve. In the same manner, memory might influence patients’ critical thinking skills. If patients’ working memory and recall is supported by visual stimuli, thereby reducing the cognitive demand on patients’ memory, it might be that these patients present with enhanced critical thinking. These factors might explain the variable executive functioning identified by the nurses and can be used as means to assist patients’ critical thinking skills. Although nurses are able to assist

patients with their reasoning and problem-solving, these are functions that will however, continue to deteriorate, as will become apparent by nurse 12's description.

Nurse 12 described a scenario where patients become aware of their deficits and struggle to come to terms with it:

N12: Sê nou in die begin stadium, **as hulle nie meer die ding kan doen nie wat hulle gewoon was te doen,...dan kan jy sien dit werk op hulle**. Want “ek kon al die tyd-, kon ek my skoene self aangetrek het.”

Translated N12: Now, say in the beginning stage, **if they can't do the thing anymore that they used to do,...then you can see they struggle with it**. Because “I could always-, I was able to put on my shoes.”

Nurse 12 illustrates, with her above example, how persons with mild AD can be aware of their loss in executive and motor functioning. Previously they were able to complete these activities of daily living. Due to the condition, they might attempt to put their shoe on, using one method. If the method is not effective, no alternative means to complete the activity is available to them, due to their cognitive flexibility limitations. As nurse 12 observed, this can cause emotional stress and feelings of helplessness in these patients. These feelings are reduced during later stages of the condition, as patients become less aware of their increasing limitations in executive functioning.

During later stages of the condition, the patients lose their ability to reason and problem-solve, as stated by nurses 1 and 10:

N1: “No, they just talk about things. They **can't solve their own problems...** They keep on talking, worrying.”

N10: “Nee, **kan nie nog redeneer** met hulle nie, somtyds. Hulle **redeneer soos kinders**.”

Translated N10: “No, **can't continue reasoning** with them, sometimes. They **reason like children**.”

Considering nurses' above-mentioned perceptions, it becomes evident that executive functioning continuously deteriorates with the progression of AD. Similar to the regression of executive functioning, patients' disorientation also increases, as apparent by the nurses' statements in the following section.

1.3.3) Increasing disorientation of persons with mild AD. The nurses found that persons with mild AD become increasingly disorientated in time and environment. Previously mentioned literature (Greeff, 2009; MacDonald et al., 2001; Maddox & Maddox, 2006; Meagher, 2001) correlates with the nurses' observations. Patients' disorientation in time and environment is visible in every sphere of their lives. As disorientation can cause paranoia, aggression and/or confusion, it would be beneficial to reduce factors resulting in additional disorientation. The nurses observed that patients' environmental disorientation worsens when a change in environment occurs. This means that persons with AD, newly admitted to a home for the elderly, might experience increased disorientation, as suggested by nurse 7:

N7: Jou oë moet so baie op hulle is en **(hulle gaan) weg dwaal van hulle omgewing af**, van kamer tot kamer of buitekant want as hulle mos nie die omgewing ken en dis Alzheimer... Vir 'n tyd lang moet ons daai **persoon so mooi rond neem tot die persoon begin raak gewoond aan sy omgewing.**

Translated N7: Your eyes need to be on them and **(they will) wander off, away from their environment**, from room to room or outside because if they don't know the environment and it's Alzheimer... For a long time, we must **take this person around so nicely, until the person starts to get used to his environment.**

According to nurse 7, persons with mild AD might become used to the home for the elderly, after a certain amount of time following the admission. However, any changes within the homes might yet again worsen disorientation as seen in the following example:

N7: Hy het in kamer 16 geslaap en dan kom daar miskien 'n sieke pasiënt aan. Nou moet onse sieke pasiënt in kamer 16 gaan. Nou moet ons vir die Alzheimer miskien 17 toe skuif. Maar die Alzheimer pasiënt het gewoond geraak aan daai 16 nommer daar op sy deur... Hy gaan terug gaan na sy 16 toe en hy gaan moeilik raak met die pasiënt wat op sy bed lê.

Translated N7: He slept in room 16 and then maybe a sick patient arrives. Now, our sick patient must be go to room 16. Now, the Alzheimer must maybe shift to room 17. But the Alzheimer patient got used to this number 16 on his door... He will go back to his 16 and he will become difficult with the patient that is lying on his bed.

As evident by the above example, environmental changes can cause greater disorientation in persons with mild AD.

Due to heightened disorientation, following changes in the environment, it was suggested by the nurses 7 and 12 that the environment should remain consistent. Nurse 12 stated the following:

N12: Los hulle goedjies op hulle gewone plekke. Want daai goed gaan vir hulle deurmekaar maak. Jy gaan nou vandag daai pasiënt daar sit en (haar) laat eet. Maar nou kyk sy in die rondte: “Ek ken nou nie die mense nie!” Sy is gewoon hier sit... **Omgewing...laat hulle in die bekende omgewing bly. Moenie vir hulle skuif nie.**

Translated N12: Leave their things in their usual place. Because those things will confuse them. Now, you will place that patient there today and let (her) eat. But, now she looks around: “I don’t know the people!” She is used to sitting here...**Environment...let them remain in the known environment. Don’t move them.**

The above-mentioned observations, show patients’ disorientation in the environment. Environmental disorientation might be the most evident and disruptive disorientation, as it can cause additional conflict in homes, evident by the example with patients being moved into different rooms. The lack of environmental orientation can be the result of spatial memory deficits (MacDonald et al., 2001). As mentioned previously, memory, including spatial memory, deteriorates during the mild stage of the condition, thus explaining the early development of environmental disorientation in persons with mild AD.

Disorientation in time was another form of disorientation the nurses noticed when caring for persons with mild AD. As previously discussed in the memory section, eight nurses indicated that persons with mild AD tend to speak about the past as if it were the present. This form of disorientation can be explained by patients maintained long-term episodic memory and their short-term memory difficulties. While they might struggle to recall the recent activities, it might be easier for them to recall past experiences. As previously discussed, information of personal relevance, acquired earlier in life, becomes more strongly consolidated and integrated within the brain (Haj et al., 2015), which might explain why persons with mild AD relive these experiences, as if they are happening in the present. Thereby they become increasingly disorientated in time, which would support nurses above-mentioned observations.

Summary of the reported ‘additional’ cognitive changes in persons with mild AD.

The nurses’ responses were categorised into three main domains, namely the tendency of persons with mild AD to create their own world, their limitations in executive functioning and

their increasing disorientation. It was identified by five nurses that persons with mild AD might consistently generate the same fictional story, believing their story to be true. At times, these stories accused nurses of lying or harming the patients. Family members regularly believed these accusations, thereby creating additional challenges for nurses.

Nine nurses reported that persons with mild AD present with limitations in their executive functioning. It was discussed that problem-solving is related to reasoning, which requires multiple thinking processes. Solving a problem is only possible if patients' attention is focused on the current task and different ways, of approaching a challenging situation, are considered. This requires cognitive flexibility compromised in persons with mild AD. Due to patients' limitations, assistance in solving problems was necessary, which the nurses attempted to provide in the homes for the elderly. The nurses found it challenging to observe persons with mild AD being aware of their cognitive deficits. Patients seemed to realise that they presented with variable executive functioning and compromised executive processes, which they struggled to come to terms with.

The nurses also observed patients increasing disorientation in time and environment. Six nurses discussed an increase in environmental disorientation of persons with mild AD. They noted that environmental disorientation was aggravated following their admission to the homes for the elderly or/and when environmental changes in the homes occurred. A suggested solution was to limit the environmental changes in the homes for the elderly. Eight nurses discussed patients increasing disorientation in time. They indicated that persons with mild AD tend to speak about the past as if it were the present.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It was of significance for the SLT to determine how the nurses perceived the cognition of persons with mild AD. These findings illustrate that the nurses perceived patients' cognitive deficits as challenging. To create a less challenging work environment, it could be beneficial to assist patients with their cognitive deficits. As stated by the American Speech, Language and Hearing Association (2016), a SLT can provide cognitive intervention to persons with mild AD. This includes providing them with stimulation exercises targeting reasoning, problem-solving and cognitive flexibility. Further SLTs can assist with strategies reducing patients' disorientation. Due to the absence of SLTs in South African governmental homes for the elderly, it would be their responsibility to assist

nurses in acquiring these stimulation skills and strategies. This would equip nurses in providing cognitive stimulation to persons with mild AD, thereby potentially enhancing patients' quality of life by maintaining or improving their cognitive functioning, whilst simultaneously reducing their work-related challenges.

1.4) Reported Communication Changes in Persons with Mild AD

Communication includes expressive language and comprehension as well as speech production. The nurses' perceptions included information for communication changes to be analysed in terms of 1.4.1) reported changes in expressive language occurring in persons with mild AD, 1.4.2) reported comprehension changes in persons with mild AD and 1.4.3) reported speech motor changes in persons with mild AD, as evident by the table below.

Table 2-1.4: Summary of the reported communication changes in persons with mild AD:

<u>1.4.1) Reported changes in expressive language occurring in persons with mild AD:</u>
-Pragmatic difficulties:
-Topic maintenance
-Topic choice
<u>1.4.2) Reported comprehension changes in persons with mild AD:</u>
-Comprehension changes daily <i>within</i> individual persons
-Longer processing times required to achieve comprehension
<u>1.4.3) Reported speech motor changes in persons with mild AD:</u>
-Changes in speech quality (e.g. slurred speech)

1.4.1) Reported changes in expressive language occurring in persons with mild AD. Persons with mild AD present with multiple impairments related to expressive language. These impairments present itself on semantic and pragmatic level (Dijkstraa et al., 2004; Samuelsson & Hyde, 2011). Eight nurses, who participated in this study, identified two pragmatic limitations, namely topic maintenance and topic choice, as apparent below.

Topic maintenance refers to the ability of persons with mild AD to formulate cohesive, coherent and concise discourse structures (Dijkstraa et al., 2004). Seven nurses stated that persons with mild AD struggle with topic maintenance, as seen below:

N5: “Hulle praat met jou oor die regte dinge...Maar **hou maar aan praat** en dan sal jy later aan sien, **hulle switch na iets anders** toe...”

Translated N5: “They speak with you about the right things... But **keep on speaking** and then you will see later, **they switch to something else**...”

N7: “Die **stories verskil maar na elke drie, derde sinnetjie** is daar iets anders wat aangaan.”

Translated N7: “The **stories change after every three, third little sentence**, there is something else that is happening.”

N11: “Wat hulle sê, dan praat hulle oor iets anderste. Dan **gaan hulle aandag** en **hulle gaan iets anderste sê**.”

Translated N11: “What they say, then they speak about something else. Then **their attention is gone** and **they will say something else**.”

The above statements illustrate that nurses observed how persons with mild AD might present with problems related to topic maintenance. Nurse 11 provides a reason, stating that a lack of attention might result in topic maintenance deficits. Other factors that might influence patients' topic maintenance include the topic under discussion and if it is of personal relevance to them or not. If it is of personal relevance, semantic recall might be more successful, consequently allowing for topic maintenance, as discussed within the memory section of chapter 3 (Haj et al., 2015). The nature of questions asked around the topic might also impact topic maintenance as it, for example, requires increased mental effort to answer open-ended question (Brookshire, 2007; Ostwald et al., 2002). Nurse 4 also realised that persons with mild AD might struggle to answer questions directly:

N4: Daar is basies 'n verskil tussen 'n persoon wat vir jou direk gaan antwoord en 'n persoon wat nie vir jou direk antwoord nie... Hy (die persoon met AD) kan praat en talk, and **he would answer but he (will) not answer the direct answer** (N4 HET KODEWISSELING GEBRUIK).

Translated N4: There is basically a difference between a person that is going to answer you directly and a person that won't answer you directly... He (the person with AD) can speak and talk, and **he would answer but he (will) not answer the direct answer** (N4 USED CODE-SWITCHING).

This perceived difficulty by persons with mild AD to provide direct answers, might also be related to the topic at hand and the cognitive resources necessary for patients to answer the

questions. The failure to provide a direct answer will negatively impact the topic maintenance of these patients. Difficulty maintaining a topic will present as a barrier to successful communication. Persons with mild AD might provide less or little information to the conversational topics, thus making it more challenging to participate in longer conversations with these patients (Carlomagno et al., 2005). This might reduce the desire of communication partners, like nurses, to attempt to engage in conversations with persons with mild AD. The nurses found that not only topic maintenance provides a challenge during conversations with these patients but also their topic choice.

Three nurses suggested that another pragmatic limitation included the topic choice of persons with mild AD, which could be a telling means to identify and diagnose the condition, as evident below:

N3: As hulle nou vir jou iets vra en jy weet nou nie wat dit is nie... Dan kyk hulle jou aan (soos): Hoe kan jy nou nie weet wat ek bedoel nie?

Translated N3: If they ask you something now and now you don't know what that is... They will look at you (like): Now, how don't you know what I mean?

N10: Jy moet met hulle kommunikeer voor jy iets agterkom (dat hulle AD het) ... Die dinge wat hulle sê wat so net nie sin maak nie, dinge wat gebeur het ... Hulle herhaal alles.

Translated N10: You must communicate with them before you notice something (that they have AD) ... The things that they say that don't make sense, things that happened... They repeat everything.

N12: "Hulle wil gesels... Luister na hulle... In daai sin is daar miskien iets, dan dink jy: **Maar die vrou het dieselfde ding vir my gesê nou die dag.**"

Translated N12: "They want to talk... Listen to them... In that sense, there might be something, then you think: **But the lady said the same thing to me the other day.**"

By means of these examples, it is apparent that the nurses noticed how persons with mild AD have difficulties in choosing a relevant topic and present with repetition of topics. They might struggle to understand that the nurses are not familiar with the topic they are discussing. The nurses' unfamiliarity of the topic can lead to communication breakdowns and frustration for persons with mild AD, as they wanted to share their thoughts with the listener and are unable to successfully formulate and/or verbalise their ideas. Depending on patients' reactions to communication breakdowns, the conversations might be terminated.

Considering the above, it becomes evident that the topic choices, the skill to maintain the topic and the repetition of topics might provide the listener with an indication that the communication partner could present with mild AD. However, the nurses felt that changes in expressive language were less obvious than memory changes in persons with mild AD. Interestingly, the two expressive language changes (more specifically pragmatic changes), as identified by the nurses, might also be linked to these patients' memory deficits. These deficits can be explained by means of the capacity theory (Miyake et al. 1994 as cited in Dijkstra et al., 2004). This theory states that the processing and storage functions of the working memory are competing for cognitive resources. Once these cognitive resources are depleted, failures in processing and storage will occur. The patients' failure to choose or maintain an adequate topic, as mentioned by the nurses, might thus be related to inadequate processing of the working memory due to high demands for the cognitive resources. Similarly, comprehension difficulties might also be explained in terms of working memory deficits and limited cognitive resources, as discussed in the following section.

1.4.2) Reported comprehension changes in persons with mild AD. The discussion involving the comprehension of persons with mild AD will include a description of the nurses' perceptions of the comprehension changes that occur due to the condition. All nurses suggested that comprehension is compromised during the mild stage of AD. Nurse 4 stated it as follows:
N4: "Hulle verstaan nie eintlik veel (van) wat jy praat nie."
Translated N4: "They don't really understand much (of) what you say."

Similar to the patients' memory, their comprehension can also change daily, *within* individual persons. This observation was reported as follows:

N3: "... somtyds verstaan hulle. Somtyds lyk dit asof hulle nie verstaan nie."
Translated N3: "...sometimes they understand. Sometimes it looks as if they don't understand."
 As with the expressive language changes, the observed changes in comprehension might be directly related to changes in memory. Comprehension might vary due to the topic and its personal relevance and experiences of persons with mild AD. Comprehension might be improved by topics of personal relevance, due to the strong integration of the information in patients' long-term episodic memory (Haj et al., 2015). Comprehension alterations could also be explained by the above-mentioned theory based on limited memory capacity (Hart et al., 1988). According to this theory, comprehension failure could occur if an excess of information were to be given to these patients. An excess of information provided would necessitate recall

of countless amounts of stored information, which could be cognitively too demanding. The high cognitive demands could exhaust the patients' memory capacity, thereby reducing the chances of information being processed or stored and thus limiting the comprehension of the information provided. The above theories might explain the nurses' observations of daily comprehension variations in individual persons with mild AD.

The nurses also suggested that the rate of comprehension was reduced. According to nurses 3 and 5, persons with mild AD required longer processing times to achieve comprehension:

N3: “Die Alzheimer’s tas mos nou die brein aan... Somtyds **kan hulle nie lekker vinnig inligting kry nie.**”

Translated N3: “Now, the Alzheimer’s affects your brain... Sometimes **they can’t get information nice and quickly.**”

N5: “**Dit vat tyd.** Dit vat regtig krag uit jou uit om met hulle regtig te kommunikeer, **laat hulle 'n bietjie kan verstaan waarom jy praat.**”

Translated N5: “**It takes time.** It really takes energy from you to really communicate with them, so that **they can understand a little bit what you speak about**”.

The nurses noticed that successful comprehension might take longer. This could depend on the topic under conversation and the presentation of the verbal output of the conversational partner. An excess of information might result in longer processing times or the inability of persons with AD to store and process information adequately, as discussed by the capacity theory. Consequently, repetitions and additional time will be necessary for comprehension to occur (Dijkstra et al., 2004).

As evident by the nurses' perceptions, persons with mild AD present with comprehension limitations. These limitations worsen during the course of the condition, to an extent in which these patients are unable to comprehend conversations. The nurses described that it is of importance to adjust verbal output, throughout the condition, in order for comprehension to be enhanced in persons with AD.

1.4.3) Reported speech motor changes in persons with mild AD. Three nurses reported alterations of the speech quality in persons with mild AD. According to them, persons with mild AD present with slurred speech and are “soft spoken”:

N2: As jy nie hulle verstaan nie, as hulle praat en jy verstaan niks nie...Dis **slurred speech**, sal ek maar sê. Dan kan 'n mens mos nie die woorde uitmaak nie... **Praat diep**

in daai mond.

Translated N2: If you don't understand them, if they speak and you understand nothing... It's **slurred speech**, I would say. Then it is difficult to understand the words... **Speak deeply within that mouth.**

N9: "They **slur** a lot. Some of them is got **soft spoken**. They will explain to you something; you won't understand."

One nurse even stated that they would provide persons with mild AD with words to repeat, so that their speech would improve. These changes in speech quality are reported to be present during the moderate to severe stages of AD (Brookshire, 2007; Rousseaux et al., 2010; World Alzheimer's report, 2009). Consequently, the nurses were asked if these speech alternations were present in persons with mild AD, which they agreed upon. The discrepancy between the nurses' experiences and literature might be explainable in terms of possible inadequate diagnosis of certain patients. The nurses might have been under the impression that these patients still presented with mild AD although their condition might have progressed to moderate or severe stages of AD. Another explanation for the discrepancy might be an overlap of stages. As a result of individual progression of the condition some persons with mild AD might already present with changes in speech quality.

To conclude the discussion related to the reported communication changes, it is of significance to mention that many of the nurses referred to the severe stage of AD. For example, nurse 8 stated that during the severe stage of AD, patients' overall communication increasingly regresses to the extent that they might become non-verbal and show limited reaction to their environment. This observation correlates with existing literature (Brookshire, 2007; Samuelsson & Hyde, 2011; World Alzheimer's Report, 2009). It is thus of importance to introduce therapeutic stimulation programmes during the mild stage of AD, to maintain and stimulate remaining communication skills for longer periods of time (Kuske et al., 2007).

Summary of the reported communication changes in persons with mild AD. All the nurses perceived the communication changes as extremely challenging. They stated that it requires a lot of energy and effort to communicate with persons with mild AD and additional effort would not necessarily ensure communicative success.

The nurses reported changes in expressive language (more specifically pragmatic changes), comprehension and speech motor abilities, following the interview question on how

communication changed in persons with mild AD. Pragmatic changes included difficulties to maintain and choose a topic. Topic choice was discussed in terms of the patients' difficulties to choose a relevant topic, a topic known to all conversational partners and the repetition of topics. Eight nurses spoke about the difficulties experienced by persons with mild AD with regard to topic maintenance or topic choice or both, whilst all the nurses reported that persons with mild AD present with changes in their comprehension abilities. The nurses discussed comprehension changes in terms of daily comprehension variations within individual persons as well as the longer processing times required to achieve comprehension. Additionally, three nurses spoke about speech motor changes in terms of changes in patients' speech quality. These changes included slurred speech and patients being soft spoken.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It was of significance for the SLT to determine how the nurses perceived the communication of persons with mild AD and the challenges thereof. The increasing difficulty, experienced by nurses, in communicating successfully with persons with mild AD might lead them to reduce the conversations they engage in with these patients. This could influence the quality of life, social and psychological well-being of persons with mild AD (McCallion et al., 1999). These influences could cause additional behavioural problems in patients, increasing the challenges experienced during their care and potentially reducing nurses' job satisfaction. To eliminate these consequences, it would be a SLT's obligation to assist nurses in improving their communication with persons with AD, by applying facilitating communicative strategies.

1.5) Reported Emotional and Personality Changes in Persons with Mild AD

N1: "... I think they are just out of their mind... They are not the same person anymore".

Following nurse 1's statement, it becomes evident that patients' personality might change drastically. This is also in accordance to Greeff (2009), who described it as individuals losing their personality. This loss or change in personality and emotions is further described within the following sections: 1.5.1) persons with mild AD tend to be perceived as assuming more child-like characteristics and behaviours, 1.5.2) persons with mild AD tend to become more aggressive, 1.5.3) persons with mild AD want to initially remain independent and 1.5.4) persons with mild AD tend to become more depressed, as indicated in the table below.

Table 2-1.5: Summary of the reported emotional and personality changes in persons with mild AD:

<p><u>1.5.1) Persons with mild AD tend to be perceived as assuming more child-like characteristics and behaviours:</u></p> <ul style="list-style-type: none"> -Perceived child-like characteristics (e.g. greater curiosity, excitement and need to be protected) -Perceived child-like actions (e.g. more protective over their belongings, want to remain in control of their possessions and present with repetitive behaviour)
<p><u>1.5.2) Persons with mild AD tend to become more aggressive:</u></p> <ul style="list-style-type: none"> -Aggression as an expression of disagreement -Aggression because of feeling belittled -Verbal aggression during mild AD vs. physical aggression during moderate to severe AD
<p><u>1.5.3) Persons with mild AD want to initially remain independent:</u></p> <ul style="list-style-type: none"> -Lack of compliance during activities of daily living to remain independent
<p><u>1.5.4) Persons with mild AD tend to become more depressed:</u></p> <ul style="list-style-type: none"> -Lack of family members visiting the persons with mild AD might aggravate depression -Signs of depression (e.g. patients become more accepting, submissive, apathetic, withdrawn and increased self-pity)

1.5.1) Persons with mild AD tend to be perceived as assuming more child-like characteristics and behaviours. Contributing to the previously discussed changes in personality, six nurses stated that persons with AD would assume more child-like characteristics, as evident by the following:

N2: “Soms van hulle is nou **soos klein kinders**... Hulle voel nou hier 'n bietjie of kyk miskien daar.”

Translated N2: “Some of them are **like small children** now... They feel a bit here or maybe look there.”

N12: “Hulle kyk so vir jou en dan dink jy, jy kyk in daai ogies soos 'n kind sin... Jy (verpleegster) is hier om my (person met geringe AD) te beskerm.”

Translated N12: “They look at you like that and then you think, you look into those little eyes like a child’s... You (nurse) are here to protect me (person with mild AD).”

N12: “Kyk, hulle sê soos jy ouer raak, raak jy weer soos 'n klein kind. En dit is so. Hulle raak net so excited of hulle voel!”

Translated N12: “Look, they say as you get older, you become like a small child again. And it is like that. They become just as excited or they feel!”

Following from the above statements, it seems that the nurses perceived persons with mild AD to become as curious and excited as children. As with children, their need to be protected also increases, as evidenced by nurse 12. These perceived child-like changes in personality are consistent with their actions, as described by nurses 8 and 9:

N8: Ek moenie vir haar kans gee om na haar kas toe te gaan nie, want dan wil sy nou **vat wat in die kas is**, want **dis hare en ons moenie daarmee werk nie**.

Translated N8: I mustn’t give her the chance to go to her cupboard, because then she wants to **take what is in the cupboard**, because **that’s hers and we shouldn’t work with it**.

N9: And I said to her (daughter of a person with AD): “You know what, your mom **is not gonna wear that (new) shoes**.” She has got the certain slipper that she will wear. She said: “You know what, I tried to get that away from her. I bought her a new one.” I said: “She is not gonna wear it” and **she is still wearing her (old) crocks**. Because **they are used to it**.

The quotes illustrate that the nurses perceived patients’ personalities to become more child-like as well as their behaviour. They become more protective over their personal belongings and do not want them to be removed or replaced (example by nurse 9). They also do not want to lose control over their belongings by permitting others to take over responsibilities for their things, as evident by patients disproving of nurses working with their belongings (example by nurse 8).

Additionally, children often present with repetitive behaviour. The nurses mentioned this also to be a child-like characteristic of persons with mild AD, as evident by the example below:

N9: **Mrs M. will come every night, 6:30, she will come to the kitchen**. You will tell her: “Mrs M.-,” you know, 7:00 o clock is tea. She will say: “**I am here to take my sleeping tablets**.” You will give her some milo and she will say: “Oh please, you need to **give me some milk. My milk is sour**.” That is **every night you will hear that...She don't change the story**.

All the above quotes illustrate that the nurses perceived persons with mild AD to assume characteristics which could be understood as more child-like. This phenomenon is the result of deteriorating cognitive functions. Their reduced reasoning, problem-solving and thinking skills cause their child-like personality and behaviours (Ostwald et al., 2002). Their limited cognitive flexibility consequently results in persons with mild AD to be overly protective over their belongings. Their cognitive limitations might not permit them to realise that the nurses are assisting them in cleaning or sorting their things. Their lack of understanding might cause them to react aggressively, especially because of their personality changes, as will become more evident by the nurses' perceptions below.

1.5.2) Persons with mild AD tend to become more aggressive. According to the nurses, persons with mild AD are not only perceived as assuming more child-like characteristics and behaviours but the majority of patients also present with mood changes. They tend to become more aggressive, as illustrated by the following nurses:

N3: “Hulle is somtyds 'n **bietjie aggressief**, van hulle... Ja, en dan het ons ook so 'n probleempie.”

Translated N3: “Sometimes they are a **little aggressive**, some of them... Yes, and then we also have a little problem.”

N6: “They like to **fight**. If you are talking to her: “Mama, can you please do that?” She is gonna say: “**No I don't want!**””

N12: “Maar hulle kan **kwaaiierig** ook word soms... “**Moenie aan my bodder nie want ek is klaar (gebad)! Hoor jy (my) nie!**””

Translated N12: “They can also get **angry** sometimes... “**Don't touch me because I am done (bathing)! Don't you hear (me)!**””

Considering the above statements, it becomes apparent, that the nurses observed persons with mild AD to become more aggressive if they want to express their disagreement. Patients might also react with enhanced aggression if they feel belittled, as evident below:

N1: “They become aggressive. It's as if **you are making them stupid...when you are opposing them.**”

According to the nurses' perceptions, persons with mild AD tend to become more verbally aggressive. Their frustration might be related to patients' inability to convey their needs (Maddox & Maddox, 2006) or feelings of being misunderstood or belittled.

However, during the severe stage of AD, physical aggression becomes more prevalent, as discussed by nurses 1 and 10:

N1: ...to the extent of **acting physically**... If he sees stones and he thinks that somebody is wrong... Cause he would ... have a clash with one person ... and he will make you understand that this person is wrong. And when he is very angry and then he can be so **aggressive and throw the stones** at that house.

N10: Somtyds as hulle so **bakleierig** is en u **wil byt** en as hulle nie wil was nie en as hulle nie wil dit nie...Soos Mev S. wat vir ons elkeen 'n **klap gee en 'n skop gee**.

Translated N10: Sometimes, if they are very **aggressive** and **want to bite** you and if they don't want to wash and if they don't want to this...Like Mrs S. who **gives each one of us a slap and gives a kick**.

Evidently, the nurses perceived the aggression of persons with AD to become more physical rather than verbal in moderate to severe stages of the condition. Decreasing verbal aggression seems to be related to the deterioration of patients' overall communicative abilities. However, as the verbal aggression decreases, patients' overall aggression seems to increase throughout the condition. An increase in patients' overall aggression might be related to their deteriorating cognitive functioning. Reduced cognitive functions result in less cognitive flexibility by patients and limited ability to problem-solve (Ostwald et al., 2002). Violence or aggression might thus seem like the only solution for persons with AD to deal with disputes, as they might lack the verbal and cognitive abilities to discuss and solve their disagreement. Interpreted in terms of the frustration-aggression hypothesis, frustration will increase as the condition progresses, due to patients increasing limitation to participate in activities of daily living, reducing their satisfaction of goals achieved over time (Berkowitz, 1989). This increase in frustration would consequently lead to an increase of aggression, explaining why patients present with increasing overall aggression throughout the condition. Aggression or disputes can also be aggravated by nurses' assisting patients during care activities and patients' desires to independently complete these activities, as evident by the nurses' statements in the following section.

1.5.3) Persons with mild AD want to initially remain independent. The nurses identified that during the mild stage of AD, patients often have the desire to remain independent. From their perspective, they have always completed certain tasks and wish to continue to do so. The reality often is that persons with mild AD might struggle to identify their limitations or remain in denial thereof, regularly resulting in fights for independence and a lack

in compliance during care activities. The nurses 1, 11 and 12 provided the following examples:

N1: I had a patient that used to tell me he doesn't need a nurse...He never applied for a nurse...And he would tell me this is the last day, this is your last day. You don't have to come tomorrow. Then when I come tomorrow, then he would tell me that I told you not to come at this time of the morning. I am busy bathing. But I would help him bath.

N11: Dan kry jy die wat hardkoppig is. As jy miskien vir hulle wil aantrek, dan sal hulle sommer jou arm wegstoot... En dan kan ons nie vir hulle aantrek nie... Ek weet dat ons partykeer sukkel. Dan trek hulle miskien weer vir hulle uit... As ons (weer) sien, dan is die een mou miskien al klaar uitgetrek... Dan mag ons maar weer alles herhaal.

Translated N11: Then you get those that are stubborn. If you maybe want to dress them, then they will just push your arm away... And then we can't dress them....I know that we struggle sometimes. Then they maybe undress themselves again...If we look (again), then the one sleeve is maybe already off... Then we may repeat everything again.

N12: Baie van hulle voel dat, hulle het altyd die werk gedoen. Ek het opgewas altyd. Ek het my eie die gedoen en dit self gedoen. Nou kom jy en verander dit hier. Jy kan nie dit doen nie.

Translated N12: Many of them feel that they always did the work. I always washed up. I always did my own this and did it by myself. Now you come and change it here. You can't do that.

The above examples illustrate how the nurses perceived a lack of compliance by persons with mild AD during activities of daily living. What comes across as lack of compliance might in fact be an attempt to hold on to independence. Sloane et al. (2007) identify that some patients present with decreased agitation and improved social behaviour, when permitted more independence during care activities. Other persons with AD favour dependence and feel too overwhelmed, when not assisted. Care activities could potentially be improved, if the nurses would observe the personality of persons with mild AD, the dependence and degree of assistance necessary and adjust care strategies accordingly. However, the nurses noticed that eventually patients will become less independent with greater deterioration of cognitive functioning. Their memory deficits, difficulties to problem-solve and/or deficits in cognitive flexibility (Ostwald et al., 2002), might reduce successful completion of various tasks and require a degree of assistance by the nurses. Previously, they might have been able to wash themselves successfully, whereas now they might forget which body parts were washed already. Taking into account the expected deterioration, as described by the nurses, persons

with AD will become progressively less independent throughout the condition, which might result in greater depression (Cassimjee et al., 2005), as will be discussed below.

1.5.4) Persons with mild AD tend to become more depressed. The nurse participants identified that persons with mild AD are likely to present with growing depressive symptoms. A factor, which could potentially aggravate depression, is a lack of family visiting persons with AD. Nurse 6 provided the following example:

N6: Maybe **she's just crying...** It's because they say: No, my, **my daughter...she didn't even come. They just put me here. They didn't even come and visit me...**

They (the patients) really need it. Because they always complain... I don't know even why they didn't come and visit me ever since she put me here. She didn't even come.

Nurse 6's observation illustrates that the absence of family members could lead to patients presenting with greater depressive symptoms. The nurses described patients' personalities as becoming more accepting, submissive, apathetic, withdrawn and with enhanced self-pity, which could potentially be signs of depression. The following quotes provide evidence for the mentioned personality signs:

N2: Al sê jy miskien van hulle familie wat nou nie gaan kom nie of het nog nooit gekom nie, of wat ook al, **hulle aanvaar dit maar net. Dit moet so wees...** As ek nou sê mos: "Daar is nie warm water nie. Ons gaan met koue water was." Dit moet so wees. Hulle gaan nie so sê: "Die water is koud."

Translated N2: Even if you speak about the family that won't come now or that has never come or something like that, **they just accept it. It must be like that...** Now, if I say: "There is no warm water. We will wash with cold water." It must be like that. They will not say: "The water is cold."

N6: It's easy because it's like a baby... Like, if you said she must sleep. Then is gonna just sleep.

N3: "Maar party is **baie teruggetrokke. En selfbejammering.** Want party van hulle, foeitog, hulle verstaan nie hoekom hulle so is nie... Wat het met hulle gebeur?"

Translated N3: "But some are **drawn back. They pity themselves.** Because some of them, ashamed, they can't understand why they are like this... What happened to them?"

N7: Wanneer dit moeilik is,...**die dag waar hulle afsny van mense...** Dan gaan jy niks uit hulle uitkry nie, al gaan jy nou uit jou paai of wat. Hulle wil niks te doen hê vandag met jou nie.

Translated N7: It becomes really difficult when-...**the day when they isolate themselves from people...** Then you won't get anything out of them, even if you go out of your way or something. Today, they don't want anything to do with you.

These quotes illustrate that the nurses perceived persons with mild AD likely to become more accepting, submissive, apathetic, withdrawn and troubled with self-pity. Nurse 3 stated that self-pity and patient's withdrawal is sometimes related to their lack of understanding regarding their condition. This lack of understanding referred to by nurse 3 is defined as anosognosia in literature (Starkstein et al., 2006). Ostwald et al. (2002) discuss patients' limited understanding about the progression of the disease, as increasing levels of fear in persons with mild AD. Enhanced levels of fear, acceptance, submission, self-withdrawal and self-pity can lead to isolation and social withdrawal (Ostwald et al., 2002), as patients become increasingly self-involved. As isolation and social withdrawal might increase so will the extent of depression. It seems that specifically persons with mild AD are more prone to be depressed due to their relatively high cognitive functioning. Higher cognitive functions might be related to patients' potential awareness of their deteriorating cognitive functioning, thus regularly resulting in greater depressive symptoms (Cassimjee et al., 2005).

Summary of the reported emotional and personality changes in persons with mild AD. The nurses discussed emotional and personality changes in terms of the tendency of persons with mild AD to assume more child-like characteristics and behaviours, their tendency to become more aggressive, their desire to initially remain independent and their tendency to present with depressive symptoms. Six nurses observed three child-like characteristics and behaviours. These characteristics included increasing curiosity, excitement and a need to be protected, whereas the child-like behaviours comprised of persons with mild AD being more protective over their belongings, them wanting to remain in control over their possessions and presenting with repetitive behaviour.

Additionally, the nurses discussed aggression in terms of its causes as well as the shift from verbal to physical aggression throughout the progression of the condition. According to nine nurses, aggression was used as an expression of disagreement or a reaction to feeling belittled in persons with mild AD. Patients might feel belittled, when they receive assistance in all activities of daily living. Persons with mild AD might react with resistance to nurses during care activities, in an effort to remain independent. The nurses interpreted this behaviour as lack

of compliance. Due to the progressive nature of AD, patients will become increasingly dependent on assistance. Greater dependence might result in them becoming more depressed. The nurses also identified the lack of family visiting persons with mild AD as potentially aggravating depression. This can be related to patients increasingly presenting as more accepting, submissive, apathetic, withdrawn and with enhanced self-pity, as mentioned by the nurses.

All nurses perceived the emotional and personality changes as challenging. The two changes that the majority of the nurses believed to be the most challenging, included the increasing aggression and depression of these patients. The increasing physical aggression was seen hazardous by the nurses. Seven of the nurses felt helpless with regards to the social withdrawal and apathy, resulting from patients' depression.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. Due to the potential influence of patients' emotional changes on the nurse-patient relationship, it was of importance to determine how the nurses perceived the emotional changes of persons with mild AD and the challenges thereof. It became evident that the nurses experienced increased stress due to patients' emotional changes. Increased stress can result in reduced job satisfaction. Additionally, emotional and personality changes can influence communication with persons with mild AD. For example, a depressed person with mild AD might become more withdrawn, resulting in less communication with others. Thus, to assist the nurses and patients, supplementary communicative strategies might be necessary. These could possibly increase communicative success, by increasing patients' participation in conversations and also motivating their participation in activities. By increasing patients' participation, they are less likely to socially withdraw from their environment, whilst potentially engaging in pleasurable activities and conversations, thereby possibly improving their mental health. Furthermore, patients' participation and improved mental health might lead to increasingly positive nurse-patient interactions, thus also improving the nurses' well-being and enhancing their job satisfaction. Consequently, a SLT's could assist nurses and patients by providing nurses with communicative strategies, facilitating their communication with persons with mild AD and assisting nurses in recognising ways of providing patients with a sense of maintained independence.

Theme 2: The Nurses' Perceptions of Their Roles in Caring for Persons with Mild AD

Taking into account the above discussion, it becomes evident that the nurses identified persons with mild AD to present with multiple perceptual, memory, cognitive, communicative and emotional changes. Due to the variety of changes and potentially improved functional abilities of patients by means of stimulation programmes in all spheres of patients' lives, multiple health care professionals should be involved caring for these patients (Burgener et al., 2008; Fuller, 2015). This could however only be possible if sufficient health care professionals and funds were available for the care of persons with mild AD. As previously discussed, South Africa exhibits a shortage of health care professionals and families of persons with mild AD and South African governmental homes for the elderly regularly have minimal funds available. Consequently, it would be unrealistic to suggest extensive therapy, involving an array of health care professionals, as this will increase the financial burden experienced by family members of persons with AD (Borochowitz, 2011; Gurayah, 2015). Thus the nurses, often being the sole health care professionals in South African homes for the elderly, are required to adopt multiple roles caring for these patients. As previously mentioned, the South African Nursing Council describes the obligations of the nurses as follows; nursing is

“...a caring profession which enables and supports the patient, ill or well, at all stages of life, to achieve and maintain health or where this is not possible, cares for the patient so that he lives in dignity until death. Accompaniment fundamental to all nursing” (Perold, 2003, paragraph 3).

Correlating with the description of nursing obligations, all nurses agreed that their role in caring for persons with mild AD included various spheres of assistance and help. For example, nurse 4 stated the following:

N4: “My rol is nou om daaglik na hulle om te sien, (om) hulle versorg met alles wat hulle wil het.”

Translated N4: “Now my role is to care for them daily, (to) care for them with everything what they want to have.”

The nurses' statements illustrated that their care included 2.1) physical, 2.2) memory, 2.3) cognitive, 2.4) communicative and 2.5) emotional spheres, as illustrated in the table below.

Table 2: Summary of the nurses' perceptions of their roles in caring for persons with mild AD:

<p><u>2.1) The nurses' need to assist with the physical care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -The nurses need to provide medication to persons with mild AD -The nurses need to assist persons with mild AD with all self-care activities -The nurses need to walk with persons with mild AD
<p><u>2.2) Nurses' roles in providing persons with mild AD with memory stimulation exercises:</u></p> <ul style="list-style-type: none"> -Direct therapy exercises targeting memory -Indirect therapy exercises targeting memory
<p><u>2.3) Nurses' role in assisting persons with mild AD with their cognitive limitations:</u></p> <ul style="list-style-type: none"> -Discussed in the following section in combination with communication
<p><u>2.4) Nurses' role in assisting persons with mild AD with their communication:</u></p> <ul style="list-style-type: none"> - Language adaptation to <i>improve</i> the communication of persons with mild AD - Adaptation of speech output to <i>improve</i> the communication of persons with mild AD - Strategies assisting with memory limitations as a means to <i>improve</i> the communication of persons with mild AD - Strategies assisting with cognitive limitations as a means to <i>improve</i> the communication of persons with mild AD - The importance of a positive mood to <i>improve</i> the communication of persons with mild AD - Adaptation of speech output <i>inhibiting</i> the communication of persons with mild AD - Requests for repetition <i>inhibiting</i> the communication of persons with mild AD - Emotional states <i>inhibiting</i> the communication of persons with mild AD
<p><u>2.5) The nurses need to provide emotional care to persons with mild AD:</u></p> <ul style="list-style-type: none"> -Importance to build a good relationship with the patients -Need to console the patients, identify their moods and reasons for their emotional states -Nurses as agents of bad news as they assume the role of patients' families (in the absence of blood relatives) -Need to keep patients happy, comforted and calm by providing security, person-centered care as well as loving and caring for them

2.1) The Nurses' Need to Assist with the Physical Care of Persons with Mild AD

The nurses discussed their involvement in different types of physical care in terms of 2.1.1) the nurses need to provide medication to persons with mild AD, 2.1.2) the nurses need to assist persons with mild AD with all self-care activities and 2.1.3) the nurses need to walk with persons with mild AD, as evident by the table below.

Table 2-2.1: Summary of the nurses' need to assist with the physical care of persons with mild AD:

<p><u>2.1.1) The nurses need to provide medication to persons with mild AD:</u></p> <ul style="list-style-type: none"> -Patients' short-term memory deficits hinder adequate administration of medication -Medication is provided to increase calmness -Consequences of the consumption of medication
<p><u>2.1.2) The nurses need to assist persons with mild AD with all self-care activities:</u></p> <ul style="list-style-type: none"> -An example of patients' preferences regarding the administration of washing activities -Importance of patient' preparation prior to the initiation of care activities
<p><u>2.1.3) The nurses need to walk with persons with mild AD:</u></p> <ul style="list-style-type: none"> -Example of nurses accompanying patients on walks -Walking as a desired activity by persons with mild AD -Continuous supervision of these patients (due to their wandering and disorientation)

2.1.1) The nurses need to provide medication to persons with mild AD. Eight nurses stated that they had to provide persons with AD with their medication. Nurse 1 for example stated:

N1: "It's to be careful with the medication that has been prescribed to them... not to be careless. They must take their medication because when they don't, it's trouble."

The main reason for the nurses distributing the medication is summarised by nurse 7 as follows:

N7: Hulle kom vir medikasie. (Hy) gaan sy pilletjie kry en na 'n tydjie, so half uur later gaan hy terug kom en sê: Hy het nog nie medikasie gekry nie. "Kan suster my medikasie vir my gee?"

Translated N7: They come for medication. (He) will get his pill and after a short time, like half an hour later, he will come back and say: He hasn't gotten his medication yet. "Can sister give me my medication?"

Due to patients' short-term memory difficulties, as previously discussed, they cannot reliably administer their own medication, which is why the nurses assume complete responsibility for patients' medication.

Medication is given to persons with mild AD to increase their calmness, as evident by the statements of nurse 5 and 4:

N5: Veral as dit nou 'n lopende resident is, jy kan mos nie aanmekaar loop nie. Wat moet ons dan doen met ander mense?... **daar is 'n pil wat hulle kry om hulle 'n bietjie rustig te maak.**

Translated N5: Especially, now if it is a walking resident, you can't walk all the time. Then, what must we do with the other people?... **there is a pill, which they get to calm them down.**

N4: "Soms van hulle is op treatments om vir hulle te **kalmeer om deur die nag te gaan slaap.**"

Translated N4: "Some of them are on treatment to **calm them, so they can sleep through the night.**"

N5: Al wat dit makliker maak is as hulle op medikasie is...dat hulle nou meer rustig kan raak. Dan kan jy nog met hulle werk, want as hulle so deurmekaar is, dan kan jy niks maak nie.

Translated N5: The only thing that makes it easier is if they are on medication...that now they can become calmer. Then you can still work with them, because if they are so confused, then you can do nothing.

According to the nurses' observations, increasing calmness leads to the inhibition of patients' constant desire to walk, induces sleep and reduces confusion. The medication seems to have a sedating effect on persons with mild AD. The nurses stated that this medication reduced the strain experienced during the care of persons with mild AD:

N5: "Want as hulle **nie op medikasie** is nie, dan is dit **moeilik** vir ons om vir **hulle te hanteer.**"

Translated N5: "Because if they **aren't on medication**, then it is **difficult** for us **to handle them.**"

Nurse 5's statement thus gives an indication that the medication might also be beneficial to nurses, reducing the strain associated with the care of persons with AD. Similar findings were evident in a German study (Kuske et al., 2009). They found that a third of persons with AD

were regularly given sedative medication to manage patients' behaviours, also considering the convenience of the nurses and other staff. Managing the behaviours of persons with mild AD, through the use of medication, might make it easier for the nurses to carry out the self-care activities outlined below.

2.1.2) The nurses need to assist persons with mild AD with all self-care activities.

As evident by the nurses' statements discussed earlier in this chapter, persons with mild AD might struggle to independently complete activities of daily living, due to their perceptual, cognitive and memory deficits. They might therefore require assistance to successfully complete various self-care activities. All the nurses agreed that their care included washing the hair and bodies of persons with mild AD. Nurse 8 made an interesting remark about the washing activity:

N8: Nou moet ek haar in die bed sommer was. Ek het al geprobeer om vir haar te stort maar ek dink dit werk nie want die vinnige water op haar lyfie is nie vir haar nie.

Translated N8: Now, I must just wash her in her bed. I tried to shower her but I don't think it works because the quick water on her body is not for her.

Nurse 8's observation shows that even when it comes to washing, patients might have preferences to the means of being washed. Nurse 7 found that taking into account their preferences might still not lead to a successful washing routine, if patients are not prepared prior to the administration of the routine:

N7: Dan sê ek: "Kom ons gaan nou was. Hier is die water... Kom, waslap nat maak en die." Jy kan nie net begin nou (die persoon met geringe AD) was nie. Jy moet nou sê: "Hier is die water. Die water is nou lou-warm." Want gaat die waslap (hulle) nou moet raak, hulle gaan jou stamp. Hulle gaan jou terugstoot. "Ek wil nie nou gewas wees nie! Die water is koud! Die water is so!"

Translated N7: Then I say: "Come we will wash now. Here is the water.... Come, damp the washing cloth and such." Now, you can't just start wash (the person with mild AD). Now you must say: "Here is the water. Now, the water is lukewarm." Because if the washing cloth must touch (them), they will smack you. They will push you back: "I don't want to be washed now! The water is cold! The water is like this!"

Nurse 7's statements shows that inadequate preparation prior to the initiation of the washing routine can result in increasing aggression. Thus, to successfully complete the washing routine, it was suggested by the nurses 7 and 8 to take into account patients' preferences and to prepare them to the washing routine prior to the administration thereof.

According to the nurses 2, 4 and 11, some persons with mild AD need to be assisted during dressing activities. The need to assist with dressing activities of persons with mild AD is likely not related to any motor difficulties experienced. As discussed earlier in this chapter, persons with mild AD often present with perceptual and cognitive changes (Dijkstra et al., 2004; Greeff, 2009; Kavcic & Duffy, 2003; Lavenua & Pasquier, 2004; MacDonald et al., 2001; Maddox & Maddox, 2006; Ostwald et al., 2002; Rizzo et al., 2000). Perceptual changes can result in spatial disorientation, which can lead to difficulties during dressing activities, for example not being able to direct one's leg into the trouser leg without assistance. Cognitive changes can result in planning and decision-making difficulties as well as procedural memory changes, which might require nurses' assistance in terms of outfit planning and the sequence in which different clothing items are put on.

Other complications that might arise due to perceptual changes, are difficulties during mealtimes, as described by two nurses. Nurse 10 for example said the following:

N10: “Maar hulle in die gange is nog fine. (Hulle) weet miskien hulle moet gaan eet. **Somtyds vergeet hulle te sit en eet.** Dan help ons maar vir hulle reg.”

Translated N10: “But those in the corridors are still fine. (They) maybe know that they must go eat. **Sometimes they forget to sit and eat.** Then we help them right.”

These difficulties, as perceived by nurse 10, might be related to the perceptual changes of persons with mild AD. Maddox and Maddox (2006) note that they might lack the feeling of hunger and hence forget to go to the dining room. Due to their perceptual changes, they might think that they finished their plate of food, without having touched it, which results in nurses having to feed these patients, as mentioned by nurse 10.

During the moderate to severe stage of AD, mealtime difficulties might also be evident as described by nurse 5 in her following statement:

N5: (Hulle) kan self nie dink om te eet nie. Dan begin jy hulle voer want hulle kan nou nie self dink en sê nie: “Haai lepel of vurk moet nou mond toe kom nie”... Dan staar hulle in die kos. Dan sal hulle niks maak met die nie.

Translated N5: (They) can't think for themselves to eat. Then you begin to feed them because now they can't think for themselves and say: “Hey, now (the) spoon or fork must come to the mouth” ... Then they stare into the food. Then they won't do anything with that.

These mealtime difficulties, observed by nurse 5, might be related to the perceptual, motor and cognitive limitations in persons with severe AD. Patients' perceptual ability might be compromised in such a way that they might not realise that there is food on their plate. This might be related to spatial difficulties previously discussed (MacDonald et al., 2001). Additionally, patients might also lack the motor ability and the procedural memory to pick up the fork or spoon and move it to their mouths, resulting in the nurses having to feed these patients, as described by nurse 5. Another activity where persons with mild AD might require nurses' assistance, is walking, as apparent by the nurses' statements in the following section.

2.1.3) The nurses need to walk with persons with mild AD. Six nurses stated that one of their responsibilities was to walk around with persons with mild AD, as summarised by nurse 2:

N2: “Ja, ons stap uit of ons sit buitekant... as dit mos nou bietjie warm is en hulle wil uitloop, dan loop ons maar uit.”

Translated N2: “Yes, we walk out or we sit outside...if it is a bit warm now and they want to walk outside, then we just walk outside.”

The nurses reported that the majority of persons with AD regularly presented with a desire to walk, as seen below:

N2: “**Hulle wil loop.** Dan vat ek hulle, dan vat ek 'n stap.”

Translated N2: “**They want to walk.** Then I take them, then I take a walk.”

The nurses' statements illustrate that they have to accompany persons with mild AD when walking. Their potential lack of orientation in places, due to their spatial memory deficits, can result in patients getting lost (MacDonald et al., 2001). Persons with mild AD might also end up occupying another patients' bed, due to their disorientation. Consequently, the majority of homes for the elderly aim to continuously supervise persons with mild AD, throughout the day and night. This correlates with the suggestion given by Maddox and Maddox (2006) to constantly supervise these patients.

Summary of the nurses' need to assist with the physical care of persons with mild AD. All the nurses believed physical care to be part of their role in governmental homes for the elderly. Their physical care was discussed in terms of providing medication, assisting with self-care activities, as well as walking with these patients. Eight nurses stated that they had to provide persons with mild AD with their medication. Their short-term memory deficits hindered adequate self-administration of their medication. Medication was provided to increase

calmness for the purpose of reducing patients' confusion, inhibiting patients' constant desire to walk and inducing sleep, thus reducing the strain related to the care of these patients.

Furthermore, all the nurses suggested their need to assist patients with their self-care activities. The nurses observed how some of the persons with mild AD experienced carrying out self-care activities as challenging, potentially due to their memory, cognitive and perceptual limitations. They also mentioned that some patients revealed preferences regarding the administration of washing activities and others required preparation prior to the initiation of the care activities.

Six nurses also believed that their role included walking with the patients. Walking appeared to be a desired activity by most persons with mild AD. However, the nurses stated how they had to then continuously supervise patients during this activity, due to their disorientation and potential to get lost even in the homes.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It is important for a SLT to identify the roles that nurses assume and how these roles can be used to enhance communication and cognition. The nurses will spend the majority of their time providing patients with physical care. It would be beneficial for the persons with mild AD, if cognitive and communicative stimulation could be integrated in these care activities. Integrated stimulation would thus assume no additional time, ideal for the nurses working under time constraints.

2.2) Nurses' Roles in Providing Persons with Mild AD with Memory Stimulation Exercises

Stimulation exercises, employed in the participating homes for the elderlies focused on enhancing the memory of persons with AD. These exercises were only applied in the two homes for the elderly collaborating with occupational therapists. According to the nurses, the occupational therapists would provide the patients with memory stimulation exercises, whilst the nurses would observe them, if time allowed for observations. The memory enhancing exercises mentioned by the nurses included 2.2.1) direct and 2.2.2) indirect therapy exercises, as apparent by the table below.

Table 2-2.2: Summary of the nurses' roles in providing persons with mild AD with memory stimulation exercises:

<p><u>2.2.1) Direct therapy exercises targeting memory:</u></p> <ul style="list-style-type: none"> -Administration of 'Spaced Retrieval Training' -Reason for direct therapy (to stimulate recall)
<p><u>2.2.2) Indirect therapy exercises targeting memory:</u></p> <ul style="list-style-type: none"> -Facilitating of games and songs -Reasons for indirect therapy (entertaining patients and to stimulate recall)

2.2.1) Direct therapy exercises targeting memory. Direct therapy exercises, proposed by the nurses, appeared to be activities reflective of the core goal of 'Spaced Retrieval Training', mentioned in chapter 1 (Lewis & Trzinski, 2006; Oren et al., 2014). As explained previously, 'Spaced Retrieval Training' is focused around providing the patient with explicit information and then shortly after, requesting the patient to repeat the information which was given to him or her. Nurse 7 stated that they would present patients with coloured blocks for example, stating the colours and shortly after requesting patients to verbalise the appropriate colours, as evident below:

N7: "Kom ons doen 5 tipe blokke. "Daai is geel, daai is rooi, daai is wit." Dan sal ons sulke goedjies uithaal en vir hulle gaan vra: "Verduidelik vir ons die kleure van die.""

Translated N7: "Let's do 5 types of blocks. "That is yellow, that is red, that is white." Then we will take out such little things and we will ask them: "Explain to me the colours of these.""

Following the explanation of the memory activity, nurse 7 provided a reason for this therapy approach:

N7: "Net so 15 minute. Net dat die mind so bietjie kan funksioneer op sy manier."

Translated N7: "Just about 15 minutes. Just, in a way, for their mind to function a bit."

By nature, these proposed exercises are focused around the recall of previously learned concepts. Through recalling information, the "mind" of the patients is "functioning", as mentioned by nurse 7. Recall stimulates areas of the frontal brain, associated with cognitive functioning (Niu et al., 2010). Improved cognitive functions might include improved memory performance. According to Oren et al. (2014), this intervention appears to benefit multiple memory deficits, including prospective, procedural, semantic and recent episodic memory.

Patients' enhanced memory functions might lead to less accusations towards nurses of lying or stealing, thereby possibly improving the nurse-patient relationships, attitudes of nurses towards the patients, their job satisfaction and the overall work-environment. This might also be achieved by means of the indirect therapy exercises, as discussed below.

2.2.2) Indirect therapy exercises targeting memory. Indirect therapy exercises proposed and performed by the nurses included playing games as well as singing with the patients. Nurse 7 stated that they played the board game 'snakes-and-leaders' with the patients, whilst nurse 3 stated that they would complete puzzles with them. Nurse 6 stated that she would sing with patients. The reasons for the three nurses engaging in such activities with patients were as follows:

N7: "Net dat die mind so bietjie kan funksioneer op sy manier."

Translated N7: "Just, in a way, for their mind to function a bit."

N3: "...vir hulle laat goedjies doen, puzzles en sulke goed, om hulle besig te hou."

Translated N3: "...to let them do little things, puzzles and such things, to keep them busy."

N6: "Now you must always think: Okay, I am gonna sing the song so that she must recall. She must recall."

The nurses' reasons for providing indirect therapy exercises thus include entertaining patients as well as aiming to improve their recall of information. The benefits of entertainment can include positive social interactions with patients, thereby resulting in 'verbal positive affect' (Levy-Storms, 2008). By means of a positive conversational and social agreement, communication is facilitated and the probability of communicative success is heightened.

The benefits of recall would be the same as discussed in relation with direct therapy. Additional benefits related to games and songs, not discussed by the nurses, can include the stimulation of other cognitive functions such as cognitive flexibility, reasoning and problem-solving (Sitzer et al., 2006). Improved cognitive flexibility, reasoning and problem-solving might also reduce conflicts in the homes for the elderly, thereby potentially enhancing the nurse-patient relationships, attitudes of nurses towards the patients, their job satisfaction and the overall work-environment.

Summary of the nurses' roles in providing persons with mild AD with memory stimulation exercises. Some nurses provided direct or/and indirect memory exercises to persons with mild AD. Direct exercise included tasks which reflected the ideals of 'Spaced

Retrieval Training', whereas indirect therapy exercises comprised of games and songs. All exercises were administered to stimulate recall. Additionally, indirect therapy exercises were performed by nurses to entertain persons with mild AD.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. A SLT's and an occupational therapist's role includes providing memory exercises to persons with mild AD. Due to the scarcity of health-care professionals in South African governmental homes for the elderly, it is the SLT's and occupational therapist's role to equip nurses with the skills to provide stimulation exercises, aimed at enhancing patients' memory. In order to recommend appropriate stimulation exercises, it was of importance to identify what exercises nurses were currently employing in the homes for the elderly.

2.3) Nurses' Role in Assisting Persons with Mild AD with their Cognitive Limitations

As previously discussed, the nurses identified the following cognitive limitations in persons with mild AD: the tendency to create their own world, their limitations in executive functioning, such as attention, and their increasing disorientation. Following the interview question related to the nurses' roles when caring for persons with mild AD, none of the nurses discussed the role of assisting patients with their cognitive limitations. The nurses did not mention specific cognitive interventions, as discussed in chapter 1. Following the question related to the challenges of communication with persons with mild AD, merely three nurses spoke about patients' attention deficits and how these can inhibit communication. As attention was only mentioned in combination with communication, it will further be discussed in the section on communication below.

2.4) Nurses' role in assisting persons with mild AD with their communication

Ten nurses mentioned their role as communication facilitator, working with persons with mild AD. They spoke about strategies in which they assisted the patients to communicate successfully. Successful communication cannot be discussed by merely taking into account expressive language or comprehension. A combination of adequate expressive language and comprehension is a prerequisite for communicative success. This can be explained by considering that the facilitation of topic comprehension might enable the listener to respond to the topic, thereby also promoting his or her expressive language. As evident, certain facilitative strategies will thus promote language comprehension and assist with production. This warrants

a discussion of strategies aimed at facilitating communication taking into account comprehension and expressive language collectively and not as two separate entities. For the purpose of this study, the communicative strategies, mentioned by the nurses, are also divided into *facilitating* and *inhibiting* strategies.

The nurses identified the following strategies aimed at *facilitating* communication of persons with mild AD, namely 2.4.1) language adaptation to improve the communication of persons with mild AD, 2.4.2) adaptation of speech output to improve the communication of persons with mild AD, 2.4.3) strategies assisting with memory limitations as a means to improve the communication of persons with mild AD, 2.4.4) strategies assisting with cognitive limitations as a means to improve the communication of persons with mild AD and 2.4.5) the importance of a positive mood to improve the communication of persons with mild AD. The nurses also mentioned factors *inhibiting* communication, which will be discussed in terms of 2.4.6) adaptation of speech output inhibiting the communication of persons with mild AD, 2.4.7) requests for repetition of information might inhibit the communication of persons with mild AD and 2.4.8) emotional states inhibiting the communication of persons with mild AD, as indicated in the table below. The majority of these strategies correlated with those discussed in chapter 1 (Adams & Gardiner, 2005; Arkin, 2007; Maddox & Maddox, 2006; Magai et al., 2002; Saddichha & Pandey, 2008; Savundranayagam & Orange, 2014). As these strategies were mentioned by ten nurses, it is likely that these are employed in their daily interactions involving persons with mild AD.

Table 2-2.4: Summary of the nurses' role in assisting persons with mild AD with their communication:

2.4.1) Language adaptations to *improve* the communication of persons with mild AD:

2.4.1.1) Pragmatic adaptation to improve the communication of persons with mild AD:

- Topic choice
- Showing a genuine interest to what persons with mild AD say
- Allowing persons with mild AD to finish their sentences or stories
- Pretending to know the topic under discussion
- Taking the side of persons with mild AD

<p>2.4.1.2) Syntactic and semantic adaptations to improve the communication of persons with mild AD:</p> <ul style="list-style-type: none"> -The importance of using simple language and specifically short sentences
<p>2.4.2) <u>Adaptation of speech output to <i>improve</i> the communication of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Reduced speed of information presentation -Influence of tone of voice and conversational style on communication (importance of calm, gentle and quiet voice)
<p>2.4.3) <u>Strategies assisting with memory limitations as a means to <i>improve</i> the communication of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Simultaneous presentation of visual and verbal stimuli -Repetition of information
<p>2.4.4) <u>Strategies assisting with cognitive limitations as a means to <i>improve</i> the communication of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Focussing undivided attention to the conversation by persons with mild AD (e.g. importance of eye contact)
<p>2.4.5) <u>The importance of a positive mood to <i>improve</i> the communication of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Good moods enhance patients' participation in conversations and activities -The nurses can influence patients' moods with their own emotional states
<p>2.4.6) <u>Adaptation of speech output <i>inhibiting</i> the communication of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Tone of voice, conversational styles and loudness can inhibit communication -Consequences of nurses' conversational styles and loud voices (e.g. aggression or sadness)
<p>2.4.7) <u>Requests for repetition <i>inhibiting</i> the communication of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Consequences of requests for repetition -Repetition as therapy technique vs aggravating irritation

<p>2.4.8) Emotional states <i>inhibiting</i> the communication of persons with mild AD:</p> <ul style="list-style-type: none"> -Bad or sad moods inhibiting the communication -Increasing excitement seems to inhibit communication

2.4.1) Language adaptation to *improve* communication with persons with mild AD.

For the purpose of this study, the nurses' statements related to language adaptation will be discussed in terms of 2.4.1.1) pragmatic adaptations to improve the communication of persons with mild AD and 2.4.1.2) syntactic and semantic adaptations to improve communication of persons with mild AD.

2.4.1.1) Pragmatic adaptations to improve the communication of persons with mild AD. As previously discussed, the nurses' observations showed that persons with mild AD present with pragmatic limitations. These limitations comprise of the difficulty initiating and maintaining conversations during the mild stage of AD (Ostwald et al., 2002). This includes difficulties in formulating cohesive, coherent and concise discourse structures (Dijkstraa et al., 2004). All these difficulties are related to the topic of the conversation. Persons with mild AD might struggle to choose, initiate or continue speaking about a topic (Ostwald et al., 2002). Depending on the topic choice, they might struggle to respond appropriately due to difficulties with verbal comprehension. The following strategies indicate how the nurses attempt to facilitate topic choice, initiation and maintenance of persons with mild AD under their care. These strategies include topic choice, showing genuine interest to what persons with mild AD say, allowing these persons with mild AD to finish their sentences or stories, pretending to know the topic under discussion and taking the side of persons with mild AD.

Topic choice. Nurse 1 discussed the importance of topic choice. She observed improved comprehension when speaking about loved ones, as evident in her following statement:

N1: "Them people, whom they love most. If you talk about his child, then **he will understand** that. When you are **talking about the stuff he loves.**"

As stated previously, information of personal relevance, assimilated earlier in life (e.g. childhood or early adulthood), is stored in the episodic memory, becoming more strongly consolidated and integrated within the brain (Haj et al., 2015). This would mean that the information of personal nature, acquired earlier in life, might be more accessible to persons with mild AD. The accessibility of such information might explain why greater comprehension is achieved when personal topics are discussed, as observed by nurse 1. The accessibility of

personal topics might also enhance the topic maintenance of persons with mild AD, as they might have additional information to contribute to such topics. The listener's reactions to patients' topics will however also determine the success of topic maintenance, as evident by the following strategy.

Showing a genuine interest to what persons with mild AD say. According to nurse 3, persons with mild AD will be more willing to communicate and respond, if genuine interest in their stories is shown, as apparent below:

N3: Dan antwoord hulle vir jou, as ek moet skielik met hulle praat en vrae vra... Dan lyk dit asof ... **daar so 'n blydsappe by hulle (is), as hulle sien jy stel belang in hulle... Dan maak hulle sommer oop.** Dan gesels hulle sommer saam met jou oor iets.

Translated N3: Then they answer you, if you suddenly speak to them and ask questions...Then it looks like...**there (is) a happiness in them, if they see you are interested in them...Then they just open up.** Then they just speak with you about something.

This is no different for persons without AD. Communication can only be maintained, successful and enjoyable if listener and speaker are genuinely interested in or motivated by the topic under discussion. In terms of the persons with mild AD, it might be challenging for the nurses, at times to show genuine interest, as their stories might be very repetitive. Multiple nurses stated that it requires patience to listen to their same stories all the time. However, although the nurses might be familiar with patients' stories, it seems that some of them allow patients to complete their stories, as apparent by the following section.

Allowing persons with mild AD to finish their sentences or stories. Nurse 9 stated that communication would be enhanced if persons with AD were permitted to finish their own sentences and ultimately their own stories, as evident below:

N9: No, I think they should finish their own thing. They should finish their own sentence. Because that is not what they want to say. Because now they want to say something else, now you finish their sentence for them. So, you rather listen to what they say, even if it's a stupid thing. You rather listen and you reply.

This suggested approach could however also lead to increasing frustration by persons with mild AD. As discussed in chapter 1, patients during the mild stage of the condition are likely to present with word-finding problems (Dijkstra et al., 2004; Samuelsson & Hyde, 2011).

Difficulties retrieving adequate vocabulary from their memory can result in pauses and circumlocutions during sentence production. In an effort to assist the patient, the listener could provide options to complete the sentences for the person with mild AD. Nurse 9 counters this approach by saying that the conversational partner might not provide the adequate options and might therefore limit the patient's personal expression. By employing either of these approaches might be strongly dependant on individual nurses and patients. Patients with strong willpower, might reject incorrect options provided by the conversational partner, to the point that they complete their sentence or story with their word or phrase of preference. It is therefore possible for the conversational partner to assist the strong-willed person with mild AD to complete their sentence and be assured that the sentence or story will be representative of what the patient aimed to say. The more submissive the person with mild AD becomes, the less helpful nurses' suggestions for sentence or story completion might become. The more submissive patients might have minimal interest and feel indifferent (Greeff, 2009) about completing their sentences and stories, thereby agreeing with all suggestions provided by the conversational partner. Additionally, it is important to determine how persons with mild AD react to the nurses' suggestions. If topic maintenance is disrupted by the nurses' suggestions, it would be beneficial to adopt nurse 9's approach, allowing patients to complete their stories. Topic maintenance might thus be enhanced by allowing patients to complete their own stories and by nurses pretending to know the topic under discussion, as evident by the following section.

Pretending to know the topic under discussion. Nurse 3 reported that at times understanding the topic being spoken about is challenging and suggested the following:

N3: Somtyds is dit nie so maklik nie want hulle praat somtyds oor goed, ...**jy weet niks daarvan nie maar hulle praat daarvan. Dan moet jy maar net maak asof jy ... weet waarvan hulle praat.** Dan sê jy dan soos jy nou dink hulle wil hê jy moet antwoord... Hulle praat miskien van 'n persoon wat hulle ken en nou dink hulle jy ken nou ook daai persoon.

Translated N3: Sometimes it is not easy because sometimes they speak about things, ...**you know nothing about it but they speak about it. Then you must just pretend you...know what they speak about.** Then you say then like you think they want you to answer...They maybe speak about a person that they know and now they think you also know that person.

By taking this approach, one, as listener, would show genuine interest in the topic under discussion. It might result in patients providing more information about their past or present experiences, thereby improving topic maintenance. A listener might thus facilitate conversational success by attempting to speak about the poorly understood topic suggested by persons with mild AD. By engaging in such a topic (e.g. the patient's restoration of paddle boats), the nurses could provide their opinions, thereby either agreeing or disagreeing with the patients' statements (e.g. his or her strategies to renovate paddle boats). Four nurses suggested that communication is enhanced by agreeing with the patient's conversational content, as evident below.

Taking the side of persons with mild AD. Four nurses found that taking the patient's side facilitates communication, as seen below:

N1: **You must take their part...**They will speak so much, they will want you to understand... You must always be: "Oh okay, **you're been quite right**" ... In the end, you think: Ag so that I can get along well with her, with him, we take their side and say: "**Yes it's like this.**"

N5: Alzheimer laat doen dinge wat hulle normally nie sou gedoen het nie. Maar **in hulle oë is dit reg** en dit moet so wees... En jy kan (hulle) nie sover kry, om te besef maar dit is nie reg nie wat jy doen nie... **Dan stem ons saam by hulle**: "Nee, jy is reg."

Translated N5: Alzheimer lets them do things that they wouldn't have normally done before. But **in their eyes, it is right** and it must be like that... And you can't get (them) so far that they realise it is not right what they do... **Then we agree with them**: "No, you are right."

N10: "Sommige dae moet jy ook maar net **saam met hulle stem** (en) saam gesels. As die een vir jou daai storie vertel en **jy weet dit is nie waar nie maar jy praat maar saam.**"

Translated N10: "Some days you also **must just agree** (and) communicate together. If this one tells you that story and **you know it's not true but you just speak together.**"

The nurses seem to have observed that taking the side of persons with mild AD, might increase the chances of patients happily providing more information, thereby maintaining the conversation successfully.

Taking patients' sides also assists in avoiding conflict as mentioned below, by nurses 1 and 8:

N1: "If you don't take part, they become **angry** cause they don't know why you don't understand this ... **This is what happened!**"

N8: “Jy moet vir hulle wys, jy glo vir hulle...Hulle raak **kwaai**. Want, “Hoekom verstaan julle my nie? **Ek praat die waarheid!**””

Translated N8: “You must show them, you believe them... They become **angry**. Because, “Why don’t you understand me? **I am speaking the truth!**””

Consequently, the nurses’ examples illustrate that it might be beneficial to take patients’ sides, if the aim of a conversation is to avoid conflict and enhance topic maintenance, as this will result in ‘verbal positive affect’ (Levy-Storms, 2008). By means of the ‘verbal positive affect’, a positive conversational and social agreement will be formed, potentially resulting in enhanced communication and a more harmonious living and working environment. Taking patients’ sides can thus be one approach to respond to patients’ conversational content.

In theory, another approach could focus on the adequacy of the conversational content provided. Taking this approach, one might aim for patients’ adequate recall. To stimulate recall, it might be beneficial to provide verbal or visual stimuli to patients, as previously suggested. These stimuli might allow patients to access their experiences in their memory, enabling them to verbalise a truly representative story (Ally, 2012; Hart et al., 1988; Maddox & Maddox, 2006; Saddichha & Pandey, 2008). Aiming for adequate recall might enhance topic maintenance, as patients’ might be able to provide more information about their previous experiences, by reliving their past. Nevertheless, patients might also think that the listener does not believe or lacks interest in their conversational topic, by trying to change their topic and hence the conversation might be terminated. Literature shows no consensus as to which approach is the most beneficial to persons with mild AD. Consequently, it is of importance for the listener to determine patients’ reactions to the above approaches, choosing the most appropriate approach for each patient.

2.4.1.2) Syntactic and semantic adaptations to improve the communication of persons with mild AD. According to the nurses’ perceptions, it becomes evident that comprehension, and hence communicative success, of persons with mild AD can be enhanced by means of syntactic and semantic adaptations. These adaptations refer to simplifications of the speaker’s expressive language, as evident by the nurses’ statements below.

The importance of using simple language and specifically short sentences. The nurses 12 and 9 suggested the use of simple language and shortened sentences. They summarised it as follows:

N12: Ek dink jy moet dit net vir hulle lekker duidelik sê. Soos in baie **klein** maak soos moontlik en **nie lang sinne** met hulle praat nie. Praat soos in: “Mevrou, ons gaan nou eet nou, ne? Lekker kos nou eet nou, ne? Okay nou. Kom ons gaan nou”...lang-, hulle gaan glad nie onthou wat was die eerste woord van my sin of party onthou bietjie... Ek glo nie 'n mens moenie paragrawe (praat nie).

Translated N12: I think you just need to say it very clearly. As in making it as **small** as possible and **don't speak long sentences** with them. Speak like this: “Madam, we will eat now, hey? Eat yummy food now, hey? Okay now. Let's go now” ... long-, they won't remember what the first word of the sentence was or some remember a bit. I don't believe a person should (speak) in paragraphs.

N9: “I think if you explain to them in a way where you **go to their level**, I think **they will understand** what you say.”

The nurses' reported experiences correlate with previously reported literature findings (Maddox & Maddox, 2006; Savundranayagam & Orange, 2014). Savundranayagam and Orange (2014) suggest that statements should be simplified by eliminating embedded clauses and providing merely one idea per sentence. The elimination of embedded clauses would evidently lead to the production of shorter sentences, as suggested by the nurses. Providing only one idea in each sentence could be a way to simplify sentences to “their (patients') level” of understanding, as suggested by nurse 9.

2.4.2) Adaptation of speech output to *improve* the communication of persons with mild AD. Six nurses identified two ways of adapting their speech output, to improve comprehension in persons with mild AD. They suggested that reducing the speed of information presentation as well as adapting one's tone of voice and conversational style might lead to communicative success, as discussed below.

Reduced speed of information presentation. One nurse observed that when information was presented at reduced speed comprehension was enhanced. She stated the following:

N6: “It helps like, when you are talking, you must talk slowly...Talk slowly and calm, if you are talking with them, so that it's easy to understand you.”

This finding is comparable to the findings previously discussed in the literature review. For example, Maddox and Maddox (2006) also mention that slow speech improves patients' comprehension. This could be explained in terms of the cognitive load during a conversation (Saddichha & Pandey, 2008). An increase in speed of presentation is directly related to an increase of the amount of information provided in a conversation. The greater the amount of information provided, the greater the cognitive load and the more cognitive functioning is necessary for the patient to understand the conversational content. However, patients' deteriorating cognitive functioning might hinder their understanding of conversations presented with increased speed, which would provide an explanation to the nurse's observations that comprehension improved with reduced speed of information presentation.

This observation and explanation nevertheless stands in direct contrast to the Savundranayagam's and Orange's study (2014). They discuss slow presentation of information as an ineffective communication strategy, burdening patients' working memory, as the retention of a whole utterance would take longer. The difference noted in the nurse's observation might be linked to her slow presentation of short sentences, thus reducing the strain on patients' working memory, by reducing the amount of information provided. The observed improvement of patients' comprehension might therefore be related to the reduced mean length utterance and not necessarily only to the reduction of the speed of information presentation. Patients' communication, including comprehension, is also enhanced by nurses' tone of voice and conversational style, as apparent by the nurses' perceptions below.

Influence of tone of voice and conversational style on communication. Five nurses seemed to observe a relationship between their tone of voice, conversational style and the willingness of persons with mild AD to communicate, as evident below:

N4: "Is mos hoe jou stemtoon is... Dit hang af hoe ons kommunikeer saam met hulle. Dis belangrik!"

Translated N4: "It's how your tone of voice is... It depends on how we communicate with them. That's important!"

N7: Dis net die manier hoe ons hulle gaan approach (dan) sal hulle teruggesels. As hulle nou nie moeilik is nie, gaan hulle teruggesels. (Dit) is net die manier hoe jy vir hulle gaan approach. Dan gesels hulle gemaklik terug met jou... As jy bietjie te hard gaan praat met hulle, dan gaan hulle ook 'n bietjie hard terug wees.

Translated N7: It's just the manner in which we approach them, (then) they will speak back. Now, if they aren't difficult, they will speak back. (It) is just the manner in which you approach them. Then they will speak back comfortably with you... If you speak a bit too loudly with them, they will also react a bit too loudly.

Five nurses observed that with a calm and gentle tone of voice and conversational style, they could convince persons with AD to participate in actions and conversations, as apparent by a few examples below:

N7: As verpleegster moet jy maar baie rustig wees en vir hulle rustig hanteer en sag maak. Jy moet maar nou saggies praat met hulle: "Ouma, kom ons drink 'n koppie koffie saam en dan gesels ons oor die probleempie, wat daar is"... Rustigheid met hulle... dan gaan hulle vir jou verstaan.

Translated N7: As nurse, you must be very calm and handle them calmly and softly. Now, you must speak softly with them: "Granny, let's drink a cup of coffee together and then we speak about the little problem, that is there" ... Calmness with them... then they will understand you.

N9: If you come in a calm way and say: "Jinne (an Afrikaans expression roughly equivalent to 'gosh') Mrs M., why did you smoke in here?" (NURSE EMPLOYS LOVING AND TEASING VOICE). Then she would say: "I didn't smoke. Who told you that?" ... She will respond to the way you are... Whoever approach them, they will respond or react to how that person is.

N10: Ek sal vir haar mooi sê: "Ek kom nou vir mevrou was." Dan sê sy: "Nee, N. het my klaar gewas." Maar ek weet mos nou, sy het haar nie gewas nie... Dan sal ek sê: "Ag kom oumie man, ek is vanoggend vroeg klaar gewerk, so kom ons gaan bad? Ek het niks om te doen nie. Kom ek bad vir jou gou-gou." So sal dit nou werk.

Translated N10: I will say to her nicely: "I will come now to wash madam." Then she says: "No, N. washed me already." But now I know, she hasn't washed her. Then I will say: "Ag come on granny, I am done with work so early this morning, so come we go bath? I have nothing to do. Come I bath you quick-quick." Now, it will work like this.

By means of the above statements, nurses illustrated that their tone of voice and conversational style can to an extent, influence the degree of participation of persons with mild AD. This observation correlates with Maddox and Maddox (2006, p. 60) who suggest that persons with AD should be spoken to in a "gentle tone of voice". A gentle tone of voice, a calm

conversational style and approaching the patient in a good mood seems to enhance patients' participation in activities and conversation.

Nurse 6 also discussed that one's tone of voice and conversational style influences patients' comprehension. She observed the following:

N6: "Talk ... **calm(ly)**, if you are talking with them, so that it's easy to understand you."

Nurse 6's observed relationship, between tone of voice, conversational style and comprehension, might not be accounted for as a direct one. The variable, responsible for the stated relationship, is probably related to patients' willingness and openness to receive new information. If information is provided in an angry or aggressive manner, patients might withdraw from the conversation, thereby reducing the communicative success. If information is provided in a calm and quiet manner, patients might be more receiving towards new information. Their openness to new information will then result in greater comprehension thereof, thereby improving the overall conversation with persons with mild AD.

2.4.3) Strategies assisting with memory limitations as a means to *improve the communication of persons with mild AD*. Five nurses identified two strategies, related to memory, which seemed to improve the comprehension of persons with mild AD. These strategies seem to assist patients' working memory, thereby reducing cognitive demands and resulting in improved communicative success. The two strategies that nurses identified included simultaneous presentation of verbal and visual stimuli and repetition of information.

Simultaneous presentation of verbal and visual stimuli. The nurses 3 and 12 observed that the simultaneous use of verbal and visual stimuli enhances comprehension in persons with mild AD, as apparent in the following quotes:

N3: As ons gesprekke met hulle voer, dan kan ons vir hulle 'n voorwerp of 'n ding,... nou miskien 'n bal... Dan sal hulle (arbeidsterapeute) vra: "Wat maak ons met die bal?" Dan sal hulle dink, wat maak hulle met die bal. Ons skop die bal, gooi of hulle speel daarmee.

Translated N3: If we have conversations with them, then we can have an object or a thing,...now maybe a ball. Then they (occupational therapists) will ask: "What do we do with a ball?" Then they will think, what do they do with the ball. We kick the ball, throw or they play therewith.

N12: “Wys vir hulle. “Ons gaan nou soontoe” (BEWEEG HAAR HAND IN RIGTING KOMBUIS). “Oooh, soontoe-kamer.” Nou weet hulle, okay soontoe, kamer toe gaan.”

Translated N12: “Show them. “Now we will go over there” (MOVES HER HAND IN THE DIRECTION OF THE KITCHEN). “Ooooh, over there-room.” Now they know, okay over there, go to the room.”

These observations, by nurses 3 and 12, support an improvement of comprehension by persons with mild AD. Hart’s et al. theory (1988), as explained above, could be the reason for enhanced comprehension in the presence of visual stimuli. The visual stimuli could act as a trigger for information recall from the short-term as well as long-term memory. Also, as discussed previously, the use of pictures or objects relevant to the topic under discussion reduces the cognitive load of conversation (Maddox and Maddox, 2006; Saddichha & Pandey, 2008). Visual stimuli will thus act as a trigger for recall, reducing the cognitive load of a conversation, thereby enhancing comprehension. Evidently, the nurses observed how an overall improvement of conversations can be reached by persons with mild AD, in the presence of visual stimuli in addition to the spoken message. Comprehension can also be improved by means of repetition, as will be illustrated by the nurses’ statements in the following section.

Repetition of information. It was suggested by three nurses that repetition of information would enhance patients’ comprehension. Nurse 6 and 11 stated the following:

N6: “If you want to understand them, you must repeat and then talk to her. No, you must do something so that she must understand.”

N11: Ek gee nie om, om 'n ding **weer te verduidelik** vir hulle. Want **baie keer verstaan hulle dit verkeerd** en dan moet jy ook verstaan, man, hou dit in jou gedagte in, dat jou pasiënt hierdie Alzheimer's dingetjie het... En jy verduidelik weer.

Translated N11: I don’t mind to **explain to them again**. Because **often they misunderstand** and then you must also understand, man, keep it in your mind, that your patient has this Alzheimer’s thingy... And you explain again.

‘Spaced retrieval training’ (Lewis & Trzinski, 2006) as previously discussed is based on repetition of information until comprehension is achieved. Thus, these nurses were unknowingly employing the ‘Spaced retrieval training’ technique, thereby improving the patients’ comprehension and memory function. By repeating information, until patients are able to understand the information, comprehension is achieved. The patients’ comprehension shows that the information is momentarily stored and processed in their memory, an indication of temporarily improved memory functions. The nurses, employing the ‘Spaced retrieval

training', were unaware that they used the same training to improve patients' memory and comprehension. To provide representative findings, the researcher decided to mention the 'Spaced retrieval training' as memory and communication strategy, thereby following the nurses' responses by discussing it as two separate strategies.

2.4.4) Strategies assisting with cognitive limitations as a means to *improve the communication of persons with mild AD.* Four nurses identified the importance of alerting persons with mild AD to direct their attention towards their conversational partners, as a means to improve their communication. As evident below, the nurses 5, 6 and 7 indicated the importance of focussed attention necessary during conversations with persons with mild AD:

N5: "Daar is baie keer waar ons met hulle (die doen): **"Kyk na my toe..."** Sou ek sê om hulle **laat terugkom na jou toe en wat jy sê.** Maar dit is hoe jy moet constantly reageer."

Translated N5: "There are a lot of times where we (do this) with them: **"Look at me..."** I would say to **let them come back to me and what I say.** But this is how you must react constantly."

N7: **Jy moet oogkontak met hulle het dat hulle kan weet waaroor jy praat...** As ons nou so gesit en gesels dan moet jy in daai gesig inkyk. Maar as jy nou agter gaan sit... dan kan hulle nie verstaan nie.

Translated N7: **You must have eye contact with them that they can know what you speak about...** If we sit and speak now, then you must look into that face. But if you would sit at the back now...then they can't understand.

As evident above, nurses 5 and 7 discussed the importance of maintaining eye contact. They suggested that all nurses should focus their attention on persons with mild AD and simultaneously encouraged patients to direct their attention towards the nurses, whilst maintaining eye contact. This is in line with Maddox and Maddox (2006), who also state that eye contact, between nurses and patients, should be maintained when speaking with persons with AD.

Maintaining eye contact was seen as equally important as focusing one's attention on one individual person with mild AD rather than a group of patients, as evident below:

N6: **If you are talking with them, don't just jump to another-...** Maybe if you are talking with her, then you are gonna talk with another one. Then she is gonna be confused...**If you are talking with her, just stick to her.**

These above-mentioned examples illustrate that nurses 5 and 7 discussed undivided attention in terms of maintaining eye contact with the patient, whereas nurse 6 reported on the

importance of nurses focusing their attention on a single person with AD rather than speaking to a group of patients simultaneously. The importance of maintaining eye contact and nurses focusing their undivided attention on one person with AD can be explained by the benefits of ‘verbal positive affect’ (Levy-Storms, 2008). By means of a positive conversational and social agreement, communication is facilitated and the probability of communicative success is heightened. If one person with mild AD is addressed, the patient might realise that he or she is being spoken to and therefore expected to react accordingly. This expectation, enhanced by maintaining eye contact, might increase the patient’s willingness and openness to receive new information and might result in improved comprehension of conversational topics. If the nurse’s attention is divided amongst multiple listeners, persons with mild AD might fail to respond to requests or statements, as they might not feel addressed and spoken to. The above illustrates that the nurses’ perceptions can be supported with literature, both showing that focussed attention might be necessary to improve communication with persons with mild AD.

2.4.5) The importance of a positive mood to *improve* the communication of persons with mild AD. It was suggested by four nurses that patients’ moods influence their conversational competence and reaction to the speaker approaching them, as seen below:

N10: Somtyds is hulle heel vriendelik, hoflik en soms van hulle kan somtyds, ook nie altyd, they also have their moods (N10 HET KODEWISSELING GEBRUIK)... En dan moet jy dit net aanvaar. Okay, dis hulle af-daggie vandag... Dan kry jy weer iets soos: “Ek wil nie!” Maar dit hang maar af van hulle moods...hoe hulle nou vandag weer is.

Translated N10: Sometimes they are very friendly, courteous and some of them can sometimes, also not always, they also have their moods (N10 USED CODE-SWITCHING) ... And then you must just accept that. Okay, it’s their off-day today...Then you get something like this again: “I don’t want to!” But it depends on their moods... how they are now, today again.

It was mentioned by nurse 3 that good moods result in better participation, as seen below:

N3: “Ja, as hulle (in ‘n) goed (bui) opgestaan het vanoggend,...dan is hulle oraait nogal. Dan kan jy baie beter met hulle werk, vir hulle hanteer.”

Translated N3: “Yes, if they got up (in a) good (mood) this morning,...then they are rather okay. Then you can work with them much better, handle them.”

The above-mentioned examples, illustrate the nurses' experiences on how the mood of persons with mild AD can affect their participation in activities and conversations. As positive affect is related to enhanced participation, one would ideally aim for patients to be in a good mood.

It is thus of interest that the emotional states of nurses or other caregivers have a great impact on the affect of persons with AD (Magai et al., 2002). This would mean that the nurses, who are in a good mood, might impact patients' moods positively, thereby simultaneously increasing patients' participation in activities and conversations. Nurse 10 seemed to have observed this phenomenon and described it as follows:

N10: Ja, maar moenie ongelukkig lyk nie. Dan gaan jy vir hulle ook laat sleg voel. Dan gaan hulle ook nou 'n bietjie down wees of gaan nie saam met jou werk of so nie... Ons moet eintlik elke dag in 'n goeie gemoed wees.

Translated N10: Yes, but you don't look unhappy. Then you will make them feel bad as well. Then they will also be a bit down or will not work with you... Actually we must be in a good mood every day.

Consequently, the above shows that nurse 10 perceived how nurses' mood and the emotional state of persons with mild AD, effect patients' participation in conversations and activities. The chance for communicative success could therefore be higher if patients and nurses are in a good mood, potentially resulting in patients' enhanced participation in conversations. These findings would support the suggestion by Norbergh et al. (2006) that in general nurses' awareness, regarding their attitudes and moods towards persons with AD and the effects thereof, should be improved.

Taking into account all of the above-mentioned facilitative strategies, identified by multiple nurses, it becomes evident that by regularly employing these strategies, nurses can enhance the communication of persons with mild AD. Similarly, by reducing the factors inhibiting communication, nurses can also facilitate communication in persons with mild AD. These factors will be discussed by means of the nurses' perceptions in the following sections.

2.4.6) Adaptation of speech output *inhibiting* the communication of persons with mild AD. Previously, it was discussed how a calm and quiet tone of voice and conversational style can result in improved participation in activities and conversations. In turn if the nurses' tone of voice or manner of addressing the patient is stressed, aggressive or in a hurry, patients' participation in activities and conversations could be compromised, as evident below:

N4: “Kyk, **as ek aggressief is**: “Kom, kom, kom!” Dan **gaan hy mos aggressief raak**. Dan gaan hy mos skel vir my: “Nee, **ek wil daarna toe gaan** of daarna toe gaan!””

Translated N4: “Look, **if I am aggressive**: “Come, come, come!” Then **he will become aggressive**. Then he will shout at me: “No, **I want to go there** or go there!””

N7: Jy kry van die nurses wat vinnig opstandig kan raak. “Ma moet nie dit doen nie! Ma moet nie daai doen nie!” Daai ene gaan nou terug (antwoord): “(Jy) moenie vir my sê ek moenie dit doen nie! (Jy) moenie vir my sê ek moenie daai doen nie!”

Translated N7: You get those nurses that quickly become rebellious. “Mom shouldn’t do this! Mom shouldn’t do that!” Now, this one will (answer) back: “(You) shouldn’t say to me, I shouldn’t do this! (You) shouldn’t say to me, I shouldn’t do that!”

N7: “As jy bietjie te hard gaan praat met hulle, dan gaan hulle ook 'n bietjie hard terug wees.”

Translated N7: “If you speak a bit too loudly with them, then they will react a bit too loudly.”

The above illustrates that nurses perceived their tone of voice and conversational style to either enhance or reduce participation in activities or conversations by persons with mild AD.

The nurses’ loudness, tone of voice and conversational style can also make persons with mild AD more aggressive or sad, as evident below:

N1: “... you make them aggressive when you speak loudly. **They think they are fighting.**”

N6: “Don't shout if you are talking with, with them. Don't shout... **They are gonna hit you.**”

N5: Of hulle **begin sommer te huil**, as jy te hard met hulle praat... Dan verstaan hulle nie hoekom praat jy nou met hulle hard... Of hulle raak, met tye raak hulle sommer **plein hartseer**.

Translated N5: Or they just **start crying**, if you speak too loudly with them... Then they don’t understand why you speak loudly with them... Or they become, at times they just become **plain sad**.

As evident by the nurses’ statements, persons with mild AD might become more aggressive or sad when spoken to loudly. These feelings might arise due to potential misinterpretations of nurses’ tone of voices and conversational styles. Persons with mild AD might interpret nurses’ loud voices as attempt to start a fight and consequently experience negative emotional changes. A person, who feels aggressive or sad, will refrain from fully participating in any activities or conversations. Thus, it was suggested by five nurses that they should attempt to remain calm, quiet and in a good mood when interacting with these patients, as this might enhance their participation in conversations.

The nurses also perceived that persons with mild AD do not only become more aggressive or

irritated when nurses speak to them loudly, but irritation is further aggravated, if the same questions are continuously repeated, as discussed in the following section.

2.4.7) Requests for repetition of information might *inhibit* the communication of persons with mild AD. Nurse 9 identified that continuous repetition of the same questions increases the irritation in persons with mild AD, as illustrated below:

N9: And it makes them irritated if you repeat every time... “Mrs A. would you like a cup of coffee?” (NURSE PRETENDS TO BE THE PATIENT). “Excuse me! Dammit man, don't you hear what I say?” ...She is irritated. I am gonna put milk in... **You can't ask them the same thing over and over because they get irritated with you.**

As much as repetition might irritate persons with mild AD, as evident by nurse 9's statement, it was also found to be an effective way to enhance comprehension in these patients. As previously mentioned, a therapy approach, namely ‘Spaced retrieval training’ (Lewis & Trzinski, 2006) is based on the principle of repetition. It is thus uncertain if the type of information being repeated would have an influence on the level of irritation experienced by persons with mild AD. Maybe the repetition of daily information (e.g. if they want milk in their coffee) aggravates the level of irritation in persons with mild AD, whereas the repetition of general personal information (e.g. weekend events or who visited) enhances comprehension instead of aggravating irritation. If future research were to find this to be true, it would be suggested to merely repeat general information, whilst refraining from repeating daily information. Thereby aiming to reduce irritating persons with mild AD and enhancing communication instead. The nurses also perceived irritation to be reduced by assisting patients with their emotional states, as discussed in the following section.

2.4.8) Emotional states *inhibiting* the communication of persons with mild AD. Four nurses identified two emotional states inhibiting the communication of persons with mild AD. These emotional states include bad or sad moods and increased excitement, as evident below.

Bad or sad moods inhibiting the communication. Previously, good moods, of persons with mild AD, were discussed as facilitative communication strategy. Being in a good mood might enhance patients' participation in conversations and activities. Conversely, bad or sad moods lead to less participation and consequently less willingness to communicate. According to nurse 3, patients need to be handled with care on such days, as discussed below:

C: As hulle nou (in 'n) sleg (bui) opstaan, wat gebeur? N3: **Dan moet jy mooi praat. Jy moet maar vir hulle pamper dan...**Hulle mood swings...sien in watter bui is hy nou weer vandag.

Translated C and N3: C: Now, if they got up (in a) bad (mood), what happens? N3: **Then you must speak nicely. You must pamper them then...**Their mood swings...now, see in what mood they are today again.

Even if patients present with negative affect, nurses encourage them to communicate, as mentioned by the nurses 3 and 6 below:

N3: “Maar ons moet altyd hulle **bemoedig om te praat**. Somtyds het hulle daar goede wat vir hulle hartseer maak... Dan probeer ons maar vir hulle verligting bring.”

Translated N3: “But we must always **encourage them to speak**. Sometimes they have stuff which makes them sad... Then we try to bring them relief.”

N6: “Mama, I am talking with you” ... I don't know what is going on. “Haai mama, I am talking with you. Please my darling.” **You must try to talk with them**. “No mama, please.” (She) just keep quiet.

Throughout this study, the nurses have discussed that persons with mild AD tend to become more aggressive, depressed and withdrawn. These personality and emotional changes might be interpreted by nurses as patients being in bad moods. It would be unrealistic attempting to entirely eradicate these moods, as they can be the result of cognitive changes (Cassimjee et al., 2005) related to anatomical changes of Alzheimer's disease (Blaszczyk & Mathys, 2007; Potocnik, 2013). The nurses, who aimed to encourage persons with mild AD to communicate regardless of their moods, conducted a promising technique. All the nurses should be encouraged to promote and enhance interactions with these patients irrespective of their moods. Additionally, the nurses should be aware of their own moods, as they might influence patients' emotional state (Magai et al., 2002). Nurses, who are in a bad or sad mood, might impact patients' moods negatively, thereby simultaneously reducing patients' participation in activities and conversations. Nurse 10 specified it as follows:

N10: **Moenie ongelukkig lyk nie**. Dan gaan jy vir hulle ook laat sleg voel. Dan gaan hulle ook nou 'n bietjie down wees of **gaan nie saam met jou werk...** Ons moet eintlik elke dag in 'n goeie gemoed wees.

Translated N10: **Don't look unhappy**. Then you will make them feel bad as well. Then they will also be a bit down or **will not work with you...**Actually we must be in a good mood every day.

Thus, to increase communicative success, nurses should aim to conceal their bad or sad moods from persons with mild AD and should continuously encourage patients to participate in conversations. Nurses should also reduce patients' excitement to achieve communicative success, as discussed in the following section.

Increased excitement seems to inhibit communication. Another factor, inhibiting communicative success, seems to include patients' sentences becoming more incoherent when excited, as mentioned by nurse 8:

N8: Ouma as sy excited raak, sal sy woorde klomp keer herhaal of die sinne deurmekaar gee...Dan kry ons glad nie 'n boodskappie nie. Nou moet jy eers weer sê: "Sit" en vir haar vra: "Wat wil ouma vir ons sê?" ...Ouma is baie keer so haastig.

Translated N8: Granny if she gets excited, she will repeat words multiple times or she gives sentences unorganised...Then we don't get the message. Now again, you must first say: "Sit" and ask her: "What does granny want to say to us?" ...Granny is often very rushed.

By means of the above, it becomes evident that communicative success could be established, if patients would be calmer when speaking, allowing for more time to produce speech. Nurse 8 aimed to achieve greater communicative success by requesting for the patient to sit down. By sitting on a chair, one's range of movement is reduced and one tends to lean back and rest on the backrest, thus requiring minimal muscular support to remain on the chair. One's muscles tend to consequently become more relaxed. Greater relaxation and reduced excitement might allow the patients to order their thoughts, which might lead to greater coherence of their sentences. Consequently, communicative success might be re-established in persons with mild AD.

Summary of the nurses' role in assisting persons with mild AD with their communication. This study categorised the reported facilitative strategies employed by the nurse participants into five main domains, namely language adaptation to improve communication, adaptation of speech output to improve communication, strategies assisting with memory limitations as a means to improve communication, strategies assisting with cognitive limitations as a means to improve communication and the importance of a positive mood to improve communication. Language adaptations, identified by the nurses, were discussed in terms of pragmatic as well as syntactic and semantic adaptations. Pragmatic adaptations included five categories, namely topic choice, showing a genuine interest to what

persons with mild AD say, allowing persons with mild AD to finish their sentences or stories, pretending to know the topic under discussion and taking the side of persons with mild AD. Taking the side of persons with mild AD was suggested by four nurses, the rest of the strategies were discussed by merely one nurse. Syntactic and semantic adaptation included the use of simple language and specifically short sentences as discussed by two nurses.

According to the nurses' perceptions, the adaptation of speech output to improve communication could be discussed in terms of reduced speed of information presentation and the influences of a calm, gentle and quiet conversational style and tone of voice. The importance of reduced speed of information presentation was discussed by one nurse whereas the influence of tone of voice and conversational style was discussed by five nurses.

The nurses identified strategies assisting with memory limitations as a means to improve communication. These included the simultaneous presentation of visual and verbal stimuli and the repetition of information. The simultaneous presentation of visual and verbal stimuli was mentioned by two nurses whereas the repetition of information was discussed by three nurses.

The nurses also mentioned strategies assisting with cognitive limitations as a means to improve communication. These strategies consisted of the importance of focussing attention on the conversation by persons with mild AD. This was discussed by three nurses in terms of maintaining eye contact between the patients and themselves as well as nurses focussing their attention on solely one person with mild AD instead of speaking to a group.

The importance of positive moods to improve communication was mentioned by two nurses. It included how patients' good mood can influence their participation in conversations and activities but also how nurses are able to influence interactions of persons with mild AD, by means of their own good moods.

The nurses discussed the factors inhibiting the communication of persons with mild AD in terms of the adaptation of speech output inhibiting communication, the requests for repetition inhibiting communication and emotional states inhibiting communication. The adaptation of speech output was discussed by five nurses in terms of the consequences of speaking aggressively and loudly to the persons with mild AD. Persons with mild AD would often misinterpret the nurses' loudness, tone of voice or conversational styles as nurses being

stressed, in a hurry or aggressive. This regularly led to patients becoming more aggressive or sad.

Requests for repetition was previously discussed as a therapy technique. It was however also discussed by one nurse as inhibiting communication as it would increase the levels of irritation experienced by these patients.

The emotional states consisted of nurses' and/or patients' bad or sad moods inhibiting patients' participation in conversations and activities, as well as patients' increased level of excitement which seemed to reduce their production of coherent and complex sentences. The effect of bad or sad moods on communicative success was discussed by three nurses, whereas the influence of increased excitement was merely mentioned by one of the nurses.

A total of ten nurses identified the above factors facilitating or inhibiting the communication of persons with mild AD. They realised that patients' communication will be improved by regularly employing the facilitative strategies and simultaneously reducing the inhibiting factors. As a collective, the nurses identified many different strategies. However, most of these strategies were merely mentioned by one or two of the nurses. All the nurses would improve their identified role as a facilitator of communication for persons with AD, by using all the above-mentioned strategies. It was promising that ten nurses acknowledged their need to be involved in assisting persons with mild AD with their communication.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. Due to the absence of SLTs in the South African governmental homes, these strategies could be employed by the nurses, during their daily care routines. As mentioned, the nurses identified many different strategies collectively. Nevertheless, most of these strategies were merely mentioned by one or two nurses and thus it would be of importance that all nurses identify and use each of the strategies facilitating or inhibiting the communication of persons with AD. It would be the SLT's role to provide all the nurses with each of the above-mentioned and some additional strategies to enhance patients' communication. Thereby, the nurses would improve their identified role as a facilitator of communication for persons with mild AD.

Additionally, two nurses considered communication to be solely the SLTs' responsibility. To assist these nurses, it would be the SLT's role to advocate the nurses' roles as communication facilitators. This might lead to nurses' applications of communication strategies. If nurses continue to believe that communication is beyond the nursing scope of practise, their application of the above-mentioned strategies might remain limited (Teri et al., 2009).

2.5) The Nurses Need to Provide Emotional Care to Persons with Mild AD

According to the nurses' perceptions, offering emotional care includes building a relationship with persons with mild AD, providing them with psychological care and assuming the role of their family, whilst assuring them that they remain as emotionally stable and comforted as possible. Due to the link between all these themes, they will be discussed collectively, as evident in the table below.

Table 2-2.5: Summary of the nurses' need to provide emotional care to persons with mild AD:

<ul style="list-style-type: none"> -Importance to build a good relationship with the patients -Need to console the patients, identify their moods and reasons for their emotional states -Nurses as agents of bad news as they assume the role of patients' families (in the absence of blood relatives) -Need to keep patients happy, comforted and calm by providing security, person-centered care as well as loving and caring for them

According to the nurses, it is necessary to build a good relationship with persons with mild AD, in order to provide true emotional support to these individuals. The nurses 4 and 7 stated the following:

N4: Ons werk elke dag en dis 'n goeie terapie ook, vir 'n verpleegster, **tussen 'n verpleegster en 'n pasiënt. Dit bou 'n verhouding.** Aan die einde van die dag is daar 'n **goeie verstaanhouding.**

Translated N4: We work every day and that's also a good therapy, for a nurse, **between a nurse and a patient. It builds a relationship.** At the end of the day, there is a **good understanding.**

N7: “Die **verhouding tussen die nurse en pasiënt...moet vir hulle gemaklik maak** om saam met hulle kan kommunikeer.”

Translated N7: “The **relationship between a nurse and patient...must make them comfortable** to be able to communicate with them.”

By building a good relationship, it becomes easier for the nurses to provide persons with mild AD with psychological support.

The nurses have to console the patients, identify their moods and reasons for their emotional states, as discussed below:

N7: Vinnig kan jy sien wanneer hulle baie teruggetrokke is. **Daai teruggetrokkenheid**, jy as nurse moet maar sit en **probeer uitvind wat dit is, wat vir hulle ongelukkig laat voel**. Wat dan miskien is dat **dit jare terug se goed is wat weer terug kom na hulle toe...** Dan vra ek vir haar: “Maar wat is jou probleempie vandag? Hoekom is jy so teruggetrokke?” Dan sal sy vir my sê: “Ek mis my ma en pa.” En dan sê sy: “Wel ja, hulle ... is gister aand werk toe.” ... Nou gaan ek maar verduidelik: “Hulle is mos nou 'n hele paar jaar oorlede.”

Translated N7: Quickly you can see when they are very withdrawn. **This withdrawal**, you as a nurse must just sit and **try to figure out what it is that makes them feel upset**. Then, what sometimes is **that things, which happened years ago, are coming back to them...** Then I ask her: “But what is your little problem today? Why are you so withdrawn?” Then she will say to me: “I miss my mom and dad.” And then she says: “Well yes, they... went to work yesterday evening.” ... Now I will explain: “Now, they have passed away a few years ago.”

Nurse 7's statement provides a good example of nurses having to console persons with mild AD. As evident consoling goes as far as working through past experiences of these patients. Nurse 8 elaborated:

N8: Want hulle vergeet en toe kom ek agter daar dat iewers is sy **ongelukkig** of sy wil vir my iets vertel en sy **weet nie hoe om dit te vertel nie**. (Dan) sal ek ook **probeer die situasie te ondersoek**.

Translate N8: Because they forget and then there I realised that she is somewhat **unhappy** or she wants to tell me something and **she doesn't know how to tell me**. (Then) I will try to **investigate the situation**.

The statement by nurse 8 illustrates that nurses need to identify the moods of persons with mild AD and determine the reasons for their moods, even if patients are unwilling or unable to provide reasons themselves.

The nurses reported that at times they aware of the reason for patients' moods as they themselves might have been the cause for them, especially in situations where it is expected of

the nurses to inform them of bad news. Nurses regularly assume the role of having to tell persons with mild AD that they were put in the homes and are to remain there, as evident below:

N2: (Dit) is nie lekker om vir hulle te sê, hulle is hier om te bly nie. Dan wil hulle ook vir jou vra: “Wil jy nou sê, my kinders het my hier gedump?” Dan sê ek: “As jy dit so stel, dit is net so.”

Translated N2: (It) isn't nice to tell them, they are here to stay. Then they want to also ask you: “Now, do you want to tell me, my children dumped me here?” Then I say: “If you put it like that, it's just like that.”

Persons with mild AD might consequently blame the nurses, become angry or accuse the nurses of lying. Following these reactions, it is the nurses' job to calm the patients.

The reason for nurses to deliver bad news, is related to the family's absence in the homes for the elderly, as evident below:

N2: “Hulle **sien baie min van hulle mense self**. So, ons as nurses is mos dan hier, is hulle mense, as hier niemand kom nie.”

Translated N2: “They **see few of their own people**. So, we as nurses are here then, are their people, if nobody comes here.”

N9: “You get so close to them, that **it's not a resident anymore. It's a family member**... You love her. It could be your mom! It could be your granny!”

The statements by nurses 2 and 9 show how they assume the role of family for persons with AD, in the absence of blood relatives regularly visiting the homes for the elderly. No reasons were given for the absence of family members in these homes. Garity (2006) found that in England, her study participants, 18 family members of persons with AD, were regularly visiting the homes for the elderly. Consequently, their family life was disrupted by continuously visiting the person with AD and often they would be unable to continue their jobs due to their time spent in the home. In the South African governmental homes for the elderly, families of persons with mild AD might not have the financial means to give up work, for their family member, or even to travel regularly to the home for a visit. It is not uncommon for them to have a substantial number of people living in a single house, as nurse 1 stated: “I am speaking from my own perspective cause we have big families in the house”. All family members need to be taken care of financially and emotionally. This might influence the frequency in which family members visit the person with mild AD. It might thus be less surprising that these family members might not visit persons with mild AD and the nurses adopt the role of family.

In becoming their family, the nurses are responsible to keep patients happy, by loving and caring for them, as explicitly stated by the nurses 4 and 5:

N4: “Dis belangrik om vir hulle **gelukkig te hou**.”

Translated N4: “It’s important to **keep them happy**.”

N4: “You must have that love. You must **give them that the love and care**. That is all they need.”

N5: “Ek dink, ons rol is maar net om vir hulle **liefde te gee**.”

Translated N5: “I think, our role is to just **give them love**.”

Three nurses further elaborated that happiness, love and care need to co-occur with feelings of comfort, calmness and security as evident below:

N9: They are used to what they have. She will have this pyjamas that she don't want to change...But then we have... to wash her pyjamas out because she want to put them on again the next night. This is something that she is used to. You can't change that! You must **do what makes them comfortable**, not what makes you as the carer or the nurse comfortable. You must **comfort your patient**.

The above statement illustrates that nurse 9 felt that nurses should be considerate and responsive to patients’ needs and comforts. She suggested that irrespective of nurses’ preferences, the patients’ benefit should be the nurses’ main concern. This approach is representative of person-centered care, as discussed in chapter 1 (Morgan & Yoder, 2011; Zimmerman et al., 2005). Person-centered care primarily takes into account patients’ needs, preferences and principles (Morgan & Yoder, 2011).

The nurses 6 and 9 discussed another means of increasing the calmness experienced by patients, through the utilisation of the person-centered approach:

N6: She will have a cup of tea now and then half an hour she will say: “You know what, the nurse didn't bring my tea yet.” Say: “Okay”, take the cup of tea. Just give her a little bit, **just to calm her**.

N9: What I will do, I maybe differ from, from the next person, I will **go along with them, just to calm** them because they tend to get very aggressive. They want you to **understand what they say**.

Nurses 6 and 9 suggested conforming to what patients say or do increases the extent of calmness experienced by persons with mild AD, due to their feeling of being understood. Calmness can also be increased by enhancing the patients’ feelings of security. Nurse 8

discussed security as one of the primary factors in caring for persons with mild AD, as seen below:

N8: “In die eerste plek moet ons vir hulle veilig laat **voel**.”

Translated N8: “In the first place, we must make them feel **secure**.”

Taking into account all the above-mentioned, it becomes evident that the nurses perceived the emotional care of persons with mild AD as multi-faceted. It will take consistent emotional involvement from the nurses to provide person-centered emotional care to persons with mild AD and might consequently result in emotional strain of nurses.

Summary of the nurses’ need to provide emotional care to persons with mild AD.

Eight nurses stated that they had to provide emotional support to persons with mild AD. A good relationship with these patients was seen as a necessity to enhance emotional care. Some nurses identified their role in keeping patients happy, comforted and calm by providing them with person-centered care and security, as well as loving and caring for them during all emotional times. During difficult times, the nurses need to console these patients, whilst identifying their moods and reasons for their emotional states. However, sometimes nurses would be the cause of patients’ emotional states, as they would act as agents of bad news. In the absence of blood relatives visiting these patients, nurses would often have to tell patients that they were put in the homes to remain there. By assuming this role and emotionally caring for these patients, nurses would adopt the role of patients’ families.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It is important for a SLT to identify the roles that nurses assume, their perception with regards to these roles and how these roles can be used to enhance communication and cognition. Due to the link between communicative success and emotional states of persons with mild AD, it was significant to identify the role and perception nurses assume in the emotional care of these patients. By supporting these patients emotionally, persons with mild AD might become more emotionally stable and optimistic, potentially leading to enhanced participation in conversations and activities. The SLT’s role would be to advocate the link between emotions and communicative success, whilst at the same time providing the nurses with communicative strategies to enhance communication.

Considering all the above-mentioned nursing roles, it becomes evident that the nurses perceive the care of persons with mild AD as multi-faceted with many challenges. Means to reduce these challenges will be discussed by considering the factors influencing the care of persons with mild AD, as described by nurses' perceptions in the following section.

Theme 3: The Nurses' Perceptions of The Factors Influencing the Care of Persons with Mild AD

Internationally, nurses working with persons with AD are more prone to present with a burnout, due to the multi-faceted care of these patients (Mobily et al., 1992). Nurses, presenting with burnout, are emotionally exhausted and might not be able to provide adequate care to persons with AD. They might become indifferent or psychologically detached from the patients, which in return might limit their involvement with the patients (Mobily et al., 1992). Due to the limited resources in South African governmental homes for the elderly, nurses adopt many additional roles potentially differentiating them from nurses in the international context. This increases the challenges related to the care of AD and exacerbates the risk of burnout in South African nurses working in these homes. It is thus of importance to establish the nurses' perceptions of factors facilitating or inhibiting the care of South African nurses, to understand and determine their needs and working contexts in which they provide and evaluate their care for persons with AD. By aiming to truly understanding the nurses' lived experiences, this study gains greater validation and can be used as a means to develop programmes, which are able to assist the nurses, keeping them at good psychological health. All factors facilitating and inhibiting the care of persons with AD will become apparent below. The nursing factors facilitating the care of persons with mild AD can be categorised in two domains, the 3.1) internal and 3.2) external nursing factors. The internal nursing factors refer to personal factors within each individual nurse, which they draw on to reduce the challenges experienced when working with persons with mild AD. The external factors refer to the interactions of nurses with the patients, fellow nurses and work strategies, facilitating the care for persons with mild AD. In addition to the behavioural changes of persons with mild AD and the challenges thereof, as discussed under theme 1, the nurses identified 3.3) an additional factor inhibiting the care of persons with mild AD, namely the lack of formal nursing training specific to the care of persons with AD. All of these sub-themes and sub-sub-themes, as discussed by the nurses, are outlined in the following table.

Table 2-3: Summary of the nurses' perceptions of the factors influencing the care of persons with mild AD:

<p><u>3.1) The internal nursing factors <i>facilitating</i> the care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -The nurses' personalities facilitating the care of persons with mild AD -Viewing caring for persons with mild AD as a learning opportunity for ones' own parents
<p><u>3.2) The external nursing factors <i>facilitating</i> the care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Patients' personality changes might improve the care of persons with mild AD -The reciprocity between nurses and patients can enhance the care of persons with AD -The peer support between the nurses facilitating care of persons with mild AD -The communication between the nurses can enhance the care of persons with mild AD -The consistency of care can enhance the quality of care for persons with mild AD
<p><u>3.3) An additional factor inhibiting the care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -The lack of formal training specific to AD

3.1) The Internal Nursing Factors *Facilitating* the Care of Persons with Mild AD

The internal nursing factors can be seen as internal coping strategies, reducing the challenges experienced by the nurses caring for persons with AD. These factors include 3.1.1) the nurses' personalities facilitating the care of persons with mild AD and 3.1.2) viewing caring for persons with mild AD as a learning opportunity for ones' own parents, as evident by the table below.

Table 2-3.1: Summary of the internal nursing factors facilitating the care of persons with mild AD:

<p><u>3.1.1) The nurses' personalities <i>facilitating</i> the care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Need for patience, empathy and tolerance -Need to remain in a good mood, positive and calm -Need for a passion for working with the elderly
<p><u>3.1.2) Viewing caring for persons with mild AD as a learning opportunity for ones' own parents:</u></p> <ul style="list-style-type: none"> -Translating the challenges of care into an opportunity demonstrates a hardy personality and cognitive appraisal

3.1.1) The nurses' personalities facilitating the care of persons with mild AD. Ten nurses spoke about the importance of certain personality traits, necessary to cope with the challenges associated with caring for persons with mild AD. Three significant character traits were identified which included patience and empathy, as apparent below:

N9: "It takes a lot of time. That, whoever wants to do nursing must know, that if you want to do nursing you must have **patience** and you must have **empathy**."

If nurses lack patience the following might happen:

N4: "So as 'n mens **ongeduldig** is, dan sometimes they also **get aggressive** (N4 HET KODEWISSELING GEBRUIK)."

Translated N4: "So if a person is **impatient**, then sometimes they also **get aggressive** (N4 USED CODE-SWITCHING)."

According to the World Alzheimer Report (2009), persons with AD should always be treated with respect and patience. This correlates with the ten nurses who stated that patience was one of the key character traits necessary when caring for these patients.

Another key personality trait includes the nurses having to present with exceptional tolerance towards patients, always remaining calm and in a good mood, as evident below:

N3: Jy moet **verdraagsaam** wees... Byvoorbeeld, somtyds as hulle so aggressief is...dan moet jy as verpleegster, dan maar **saggies vir hulle hanteer** en vir hulle gemaklik laat voel en vir hulle laat veilig voel.

Translated N3: You need to **tolerate a lot**...For example, sometimes if they are so aggressive...then you as a nurse must then **handle them with care** and make them feel comfortable and make them feel secure.

The nurse's example shows that no matter how challenging, nurses are meant to react with patience, empathy and remain in a good mood. It is reasonable to say that any human would be challenged, when asked to continuously and consistently react positively to potentially negative environments. It is thus not surprising that six nurses discussed the importance of being passionate about their jobs in the homes, as evident by the two examples below:

N5: Ek het nog nooit agtergekom (dat) voor my of agter my miskien, dat nurses in 'n debate sal gaan met die residents. En daarvoor is dit baie belangrik dat **jy 'n passie het vir nursing, anderste behoort jy nie hier nie**.

Translated N5: I have never realised (that) in front of me or maybe behind me, that nurses will enter into a debate with residents. And for that it's very important that **you have a passion for nursing, otherwise you don't belong here.**

N12: "Jy moet 'n passie het vir die werk anders hoort jy nie hier nie."

Translated N12: "You must have a passion for the work otherwise you don't belong here."

Taking into account all the above-mentioned core personality characteristics, mentioned by multiple nurses, it becomes evident that this personality type is representative of the hardy personality described in literature (Florian et al., 1995). The hardy personality is based on three concepts, namely commitment, control and challenge. A hardy person is

easily committed to what they are doing in their lives, believe that they have some control over the causes and solutions of life problems, and view changes in life and adaptive life demands and challenges as opportunities for growth rather than as threats (Florian et al., 1995, p. 687).

As evident by the discussion above, the nurses who participated in this study seem to present with hardy personalities in terms of *commitment*, *control* and *challenge*. The nurses' work *commitment* becomes evident by their aim to remain in a good mood and react positively to a challenging environment. Their statement, that being passionate about their work is essential and without passion one should not be working in the homes for the elderly, furthermore illustrates their *commitment*. The nurses hold some *control* over the outcome of the functioning of persons with mild AD, by adopting multiple roles when caring for these patients. Even though these nurses perceived their roles as *challenging*, they also identified their opportunity to build relationships with these patients. They mentioned that persons with mild AD would become like family to them. Furthermore, the *challenges* related to the care were also perceived as personal learning opportunities by two nurses, as will be discussed below. Concluding from the above, it becomes evident that these nurses present with a hardy personality, which allows for enhanced patience, empathy and tolerance when working with persons with mild AD. This is of significance, especially within the South African governmental homes for the elderly, as these nurses are often solely responsible for the care of persons with mild AD, with no support from patients' families or other health care professionals. Without a hardy personality, their risk for burnout would potentially be exacerbated, which would in return influence the quality of care (Mobily et al., 1992). As these nurses might be the only social contact for persons with mild AD (besides fellow-residents), a change in care will be directly related to the quality of

life experienced by these patients. Nurses reducing their quality of care might thus lead to a decrease of patients' quality of life.

The benefits, related to hardy personalities of these nurses, are equivalent to the findings by Kobasa (1979), who also suggests that this personality type reduces the challenges experienced by study participants. However, the findings of Kobasa (1979) and Mobily et al. (1992) stand in direct contrast to the findings by Rodney (2000). He examined nurses' hardy personality in situations where persons with dementia would become aggressive and found that their experienced stress is not reduced by means of their personality. The discrepancy between the results of the different studies could be attributed to all factors examined, other than the personality type. Rodney (2000) chooses to examine aggression as a factor and its interaction with hardy personalities. It was suggested by the nurses in the current study that aggression is the most difficult challenge when working with persons with mild AD. Thus, the findings of the current study might have been similar to Rodney's (2000), if merely examining hardy personalities and its benefit in reducing stress experienced in the presence of aggression, would have been examined. However, the current study focused on all the challenges, thereby including many more factors other than aggression. The nurses' reports of the collective challenges and the resulting stress that they experience, demonstrate enhanced coping attributed to their hardy personalities and cognitive appraisal, as will be discussed in the following section.

3.1.2) Viewing Caring for persons with mild AD as a learning opportunity for ones' own parents. As mentioned previously, two nurses also stated that they saw the skills they were developing as something that they could use, should it be necessary for their own parents, as evident below:

N4: "Like for instance if I got a mother, if she go in that state, then I know exactly what is the procedure and what I must do."

N7: "Ek begin nou myself aanleer, as my ouers moet ouer raak. Dan gaan ek aan die einde van die dag weet hoe om met hulle te kan reg werk."

Translated N7: "I am starting to teach myself, for when my parents must get older. Then, at the end of the day, I will know how I can work with them correctly."

These two nurses identified their opportunity to learn from their experience of working with persons with AD, as skills they could employ should their own parents develop AD in future. Identifying the learning opportunity and converting a challenging environment to a learning

opportunity, these nurses demonstrate the above-discussed hardy personality (Florian et al., 1995) and cognitive appraisal (Rodney, 2000). According to Folkman et al. (1986, p.993), cognitive appraisal is “the process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being and, if so in what ways”. These two nurses aimed at taking care of their parents eventually, thereby reflected the notion of Ubuntu (Gurayah, 2015), as specified in chapter 1. Providing their parents with the best quality of care would then also benefit them and their well-being as carer. They saw their encounter with persons with mild AD as a means to acquire knowledge and exposure to persons with AD, for the purpose of taking care of their parents in future, if they were to present with AD. However, even though their current care was also a means to assist their parents in old-age, it became evident throughout the interviews that both nurses were passionate about their jobs, in the homes for the elderly. These nurses thus converted a challenging situation into a learning opportunity by reflecting on the ways it could personally benefit them in future. This provides a means for the nurses to reduce the experienced challenges and remain in better mental health, even when assuming the multiple previously-mentioned roles in the South African governmental homes for the elderly. Thereby, these nurses can continue providing enhanced quality of care and consequently an improved quality of life to persons with mild AD.

These benefits of cognitive appraisal on reducing stress in caregivers, including nurses, are coherent with the study by Mittelman et al. (2004). They state that interventions related to cognitive appraisal, provide caregivers with enhanced coping strategies and reduced symptoms of depression. Even though it is likely, that the nurses in the current study would benefit from such interventions, it is uncertain if enough resources in the homes for the elderly are present for the nurses to be offered and provided with such interventions. It is thus promising that some of the nurses are already ‘spontaneously’ employing cognitive appraisal already.

Summary of the internal nursing factors facilitating the care of persons with mild AD. Collectively, the nurses identified two internal factors facilitating their care of persons with mild AD, namely their personalities and viewing caring for persons with AD as a learning opportunity for potentially taking care of their own parents. Ten nurses discussed the personality traits, such as patience, passion, empathy and tolerance, as key traits for successful caretaking in homes for the elderly. Furthermore, irrespective of how challenging a situation could get, nurses sensed an unspoken and/or spoken expectation by others, like family

members, that they should always react positively, calmly and be in a good mood. This personality type has been discussed as a hardy personality in literature and has been proven as a beneficial means to overcome stress in previous research studies.

Two nurses mentioned that caring for persons with mild AD offered them a learning opportunity for their own parents, should they be affected by AD in future. They therefore viewed the opportunity offered by the challenges, thereby demonstrating a hardy personality and cognitive appraisal. For the two nurses, who spoke about taking care of their parents in future, it was of importance to gain as much knowledge and experience involving AD, thereby possibly enabling them to provide their parents with the best quality of care and simultaneously enhancing their own well-being by fulfilling their role as a carer. Cognitive appraisal has also been proven as beneficial means to overcome stress in other studies than the current study.

Interestingly, ten nurses in the current study spontaneously mentioned character traits enhancing the care of persons with mild AD, whereas merely two nurses referred to their care as a learning opportunity for perhaps having to care for their own parents, if they were to be affected by AD in future.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. The relevance for a SLT to determine the internal nursing factors will be explained following the discussion of the external nursing factors. The internal and external nursing factors are of relevance to the STL for the same reasons and will therefore be discussed together.

3.2) The External Nursing Factors *Facilitating* the Care of Persons with Mild AD

The external nursing factors can be seen as external coping strategies, reducing the challenges experienced by the nurses during the care of persons with mild AD. These external factors, identified by the nurses, are outlined by the following 5 sub-sub themes: 3.2.1) patients' personality changes might improve the care of persons with mild AD, 3.2.2) the reciprocity between nurses and patients can enhance the care of persons with AD, 3.2.3) the peer support between the nurses facilitating care of persons with mild AD, 3.2.4) the communication between the nurses can enhance the care of persons with mild AD and 3.2.5) the consistency of care can enhance the quality of care for persons with mild AD, as indicated in the following table.

Table 2-3.2: Summary of the external nursing factors facilitating the care of persons with mild AD:

<p><u>3.2.1) Patients' personality changes might <i>improve</i> the care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Patients' submissiveness results in enhanced co-operation -Patients' motivation to participate in activities enhances care -Reduced nursing stress and risk for burnout with increasing co-operation and motivation of patients
<p><u>3.2.2) The reciprocity between nurses and patients can <i>enhance</i> the care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Identifying patients' needs and preferences -Patients increasing appreciation for nurses, as they become more responsive to patient-specific needs and preferences -Reciprocity and its effect on nurse-patient relationships and nurses' job satisfaction
<p><u>3.2.3) The peer-support between the nurses <i>facilitating</i> care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Peer-support as coping strategy -Benefits of peer-support in South Africa
<p><u>3.2.4) Communication between the nurses can <i>enhance</i> care of persons with mild AD:</u></p> <ul style="list-style-type: none"> -Communication between nurses and across nursing shifts
<p><u>3.2.5) The consistency of care can <i>enhance</i> the quality of care for persons with mild AD:</u></p> <ul style="list-style-type: none"> -Consistency of care to increase feelings of calmness and security in persons with mild AD -The suggestion that patients should be assigned to an individual nurse daily

3.2.1) Patients' personality changes might *improve* the care of persons with mild AD. Previously, it was discussed that some patients might become more submissive with the onset of the condition. Two of the nurses stated that this alteration of their emotional states results in greater co-operation, thereby reducing the stressors of care, as seen by the following statement:

N2: Soms van hulle...wil heeltyd beweeg. As jy nou vir hulle sê: “Dit dis nou etenstyd. Ons gaan nou sit en eet.” Dan **gaan hulle nou stil sit**. Dan **gaan hulle nou wag** vir ete, al is dit nou nie etenstyd nie...**Hulle luister**.

Translated N2: Some of them...want to move the whole time. Now, if you say to them: “It’s time to eat now. We will sit and eat now.” Then **they will sit** still now. Then **they will wait** for food now, even if it isn’t time to eat yet...**They listen**.

The nurses seem to have observed that some persons with mild AD might tend to not only present as co-operative but often also as motivated to participate in activities, due to the noted submissiveness, thereby enhancing their care, as evident below:

N3: “Hulle is nogal **werksamig**. Hulle werk saam...Maar hulle is altyd **ywerig** om (oefeninge) te doen want hulle wil deelneem. Hulle **stel belang**. Hulle wil deelneem aan die proses.”

Translated N3: “They are **willing to participate**. They co-operate. ...But they are always **keen** to do (exercises) because they want to participate. They are **interested**. They want to participate in the process.”

This observation stands in direct contrast to the study conducted by Greeff (2009), who found a decline in patients’ interest in activities. The contrasting findings might be accounted for by individual differences of patients’ degree and symptoms of AD. Irrespective of the contrasting findings and the cause thereof, three nurses in the current study found persons with mild AD to be more co-operative and motivated. From the above, it becomes clear that these nurses view greater co-operation and motivation to participate as enhancing and simplifying care activities. They perceived these characteristics as reducing the stressors associated with the care of persons with mild AD. Greater co-operation and participation from patients is more likely to results in a positive work-environment, in which activities of daily living could more easily be completed. This could reduce the stress experienced by the nurses, which could lead to enhanced well-being and improved relationships between nurses and patients. This is of significance, especially in South African governmental homes for the elderly, where the nurses are expected to adopt many challenging roles daily. If the effort and strain to complete some daily activities is reduced by patients’ co-operation, it could decrease nurses’ workloads and afford them more time to spend on positive interactions with persons with mild AD. By reducing the workload and associated strain, the nurses are less likely to present with burnout and are more capable of providing enhanced quality of care, by means of enhanced nurse-patient communication (Heyns et al., 2003; Le, 2008; Mobily et al., 1992). This benefits persons with mild AD as they regularly have no family visiting and they could become lonely if they were not to engage with the nurses and other residents. By means of engagement

between the nurses and patients, enhanced reciprocity can be achieved, as described by the nurses' perceptions below.

3.2.2) The reciprocity between nurses and patients can *enhance* the care of persons with mild AD. The benefits of a reciprocal relationship with the patients was discussed by five nurses. Firstly, the nurses spoke about the importance of identifying patients' needs and preferences and act accordingly, as evident below:

N1: "You have to **know them**...so that you would know how **to get along with them**... You would know their **likes and dislikes**."

N12: "'n Mens moet dink aan **hoe met hulle optetree en leer ken daai persoon** so goed soos jy kan. En weet waarvan daai persoon **hou**."

Translated N12: "A person must think about **how to handle them** and **get to know that person** as best you can. And know what that person **likes**."

The nurses found that they were more responsive towards persons with mild AD, when aware of their needs and preferences. This knowledge enables the nurses to suggest appropriate activities for these patients, thereby supporting and comforting them, by conforming to their desired activities. Their improved responses to patients' needs and preferences is representative of the person-centered approach, as described in chapter 1 (Morgan & Yoder, 2011; Zimmerman et al., 2005). Supplementary to the benefits of using a person-centered approach, it also enhances the nurses' relationships with persons with AD, as evident by nurse 3's statement:

N3: "Daar (is) so 'n blydskappe by hulle, as hulle sien **jy stel belang in hulle**... Dan maak hulle sommer oop. Dan **gesels** hulle sommer saam **met jou** oor iets."

Translated N3: "There (is) such a happiness in them, if they see **you are interested in them**...Then they just open up. Then they just **speak with you** about something."

Nurse 3's observation shows how beneficial an interest in and knowledge about patients' needs and preferences can be in encouraging communication with persons affected by mild AD, thereby establishing and enhancing nurse-patient relationships. Nurse-patient relationships are therefore improved by patients increasing willingness to "open up" and engage in conversations. Sheldon et al. (2006, p.141) goes as far in saying that "communication is a cornerstone of the nurse-patient relationship. The power of effective nursing is strengthened and enriched by good communication". Good communication, also regularly referred to as patient-centred communication (McCabe, 2004), is possible when the nurses are aware of patients' interests, as described by nurse 3. This knowledge would enable the nurses to choose

topics that patients prefer thus possibly increasing the probability of patients engaging in a conversation, as previously discussed. Enhanced communication could therefore lead to a positive nurse-patient relationship which in return could also result in greater participation by persons with mild AD following nurses' requests. Nurses in other studies, including the current study, seem to share this perception (Sheldon et al., 2006).

Some of the nurses perceived that patients' appreciation for them will increase, when they become more responsive to the patients' needs and preferences, as apparent by the following example:

N7: Nou eendag het hulle vir haar kom uitboek vir twee dae. Toe is ek besig om haar goeds in te pak en alles... Sê ek vir haar: "Lekker kuier!" Sy gaan stap 'n entjie. Dan **draai sy terug van die kinders af** en toe sê sy: "**Ek het vergeet om jou te groet.**" Sy **soen nou vir my** op die wang en sy sê: "Sien jou wanneer ek terugkom."

Translated N7: Now one day, they booked her out for two days. Then I was busy to pack her things and everything... I say to her: "Enjoy the visit!" She walked a short distance. Then **she turns away from her children** and then she said: "**I forgot to greet you.**" Now, **she gives me a kiss** on my cheek and she said: "See you when I come back."

It is apparent by the nurse's example that patients become responsive and appreciative towards them, when a good relationship is established, a relationship built on reciprocity. In the United States, nursing aids discuss the importance of awards, like appreciation, and its impact on job satisfaction (Castle, 2007). The same is true for South African nurses. Greater appreciation would increase nurses' job satisfaction, which would lead to an improvement of care and nurses potentially adopting the roles of primary caregivers or family of persons with mild AD. Again, a phenomenon which is not unique to South African nurses but is also reported by a nursing assistant in the United States. She stated: "I love my patients, I do. And I think they know that, too. You know, 'cause we're family to them" (Secrest et al., 2005, p. 94). This is equivalent to what nurse 9 stated:

N9: You get so used to it, you get so close to them, that **it's not a resident anymore.**

It's a family member... You love her. It could be your mom! It could be your granny!

This nurse-patient relationship is of significance in the South African governmental homes for the elderly, where family is regularly absent and nurses are often the only social contact for persons with mild AD. Consequently, enhanced care, by optimising communication and simultaneously improving the nurse-patient relationships, would be of even greater importance

for the nurses and the patients. Care can further be improved by peer-support between nurses, as discussed below.

3.2.3) The peer-support between the nurses *facilitating* care of persons with mild AD. The nurses stated that during times when caring for persons with AD becomes more challenging, they become their own support system, as evident below:

N2: Dan sien ek: Okay, haai dis te moeilik...Jy sal net sê: “**Sterkte suster, sterkte!**” Dis maar al wat jy nodig het... Dan gaan ons maar net weer aan...Die mense, wat ek nou mee werk, **ons is eintlik 'n span**.

Translated N2: Then I see: Okay, hey that’s too difficult...You will just say: “**Good luck sister, good luck!**” That’s all that you need ... Then we will just continue...The people, that I am working with now, **we are actually a team**.

The nurses mentioned no external psychological support apart from the peer-support offered by colleagues. It comes across as if there might be little external support for the majority of the nurses working in homes for the elderly. This correlates with findings by Brodaty et al. (2003), who emphasise the strain involved in caring for persons with AD and the lack of psychological support to cope with the strain. According to them, this could lead to a lack of job satisfaction. Due to the focus of this study, the relationship between job satisfaction and the lack of psychological support, in the governmental homes within the Tygerberg district, was not determined. This study can merely confirm that the nurses themselves seem to be their greatest support system.

Peer-support, as a coping strategy, is not something novel to the nurses working in South African governmental homes for the elderly. Its benefit has led to the formation of formal support or focus groups, assisting nurses to discuss their challenging experiences (Mobily et al., 1992; Sheldon et al., 2006). Internationally nurses seem to perceive peer-support as most helpful, as fellow nurses, working in the same facility, would have enhanced understanding regarding the challenges specific to their working environment. It is thus promising that two nurses in the current study also mentioned peer-support, as a coping strategy. These nurses might therefore reduce the stress experienced by assisting one another and potentially decreasing the chances of burnout or a lack of job satisfaction. An additional benefit is that peer-support is cost-effective, which is beneficial for the South African governmental homes for the elderly. As minimal resources might be present in these homes, coping strategies like peer-support are viable options for the nurses to overcome challenging experiences. Overall, it

would be beneficial if communication between nurses is increased, not only for psychological support but also to improve the quality of care, as will become evident by the nurses' statements in the following section.

3.2.4) Communication between the nurses can *enhance* care of persons with mild AD. Three of the nurses also indicated that communication between the nurses and across nursing shifts could enhance the care for persons with mild AD, as summarised by nurse 8:

N8: Hulle (persone met geringe AD) vergeet baie. Ons moet vir hulle baie keer dink en daar is so baie dinge wat ons moet doen. Ons kan nie by alles kom nie... So, daarom het ons mos nou die sisteem. As ons iets geprobeer het, dan probeer ons dit **oordra aan onse volgende kollegas**, wat nou die volgende dag werk.

Translated N8: They (persons with mild AD) are very forgetful. Often, we need to think for them and there are so many things that we need to do. We can't do everything... So now that's why we have the system. If we tried something, then we aim to **transfer it to our next colleagues**, who now work the next day.

Communication between the nursing shifts increases the work effectiveness as nurses are less likely to perform the same routines twice, not aware that it has been completed by the nurse, on the previous shift. Without proper communication between nurses, they might thus fail to complete or repeat care activities, thereby compromising the quality of care experienced by persons with mild AD. Communication is only sufficient if verbal or written reports are available, with enough detail for nurses to identify what is required (Siegel & Young, 2010). It was found that nurses merely report on 40% of their activities, if time allows for documentation (De Marinis et al., 2009). Siegel and Young (2010) found that reports are regularly insufficient, leaving carers, including nurses, uncertain about the duties during their shift. Taking into account these findings, it becomes apparent that communication is not only important but also the detail thereof, which is also time-consuming. As nurses, working in South African governmental homes are already pressured for time to complete their duties, it might be of interest to determine the presence and detail of reports across nursing shifts. It might be that some of the governmental homes might have limited or no communication across shifts, due to the time-limitations arising from the poor nurse-patient-ratio, as will be discussed later. Reason for this assumption is grounded in the observation that the three nurses, who spoke about reports across nursing shifts and the benefit thereof, were all employed in the same home for the elderly. This might be an indication that communication is particularly problematic in this specific institution. It might be necessary to advocate for improved documentation

procedures and communication across shifts in South African governmental homes for the elderly, to enhance the quality of care of persons with mild AD and potentially reduce the workload of the nurses and optimise their time management. More detailed documentation and communication between shifts can also enhance the consistency of care, as evident below.

3.2.5) The consistency of care can enhance the quality of care for persons with mild AD. The nurses identified that greater consistency of care provided by nurses might assist the person with mild AD in predicting and anticipating what routine is to follow. The manner in which each nurse executes a routine might differ, due to personal preferences of nurses. Knowing what and who to anticipate might increase feelings of calmness and security in persons with mild AD, also resulting in improved care. Nurse 8 went as far as suggesting that one nurse should be responsible for the same patient for an entire day, to ensure consistency of care for persons with mild AD:

N8: As ek heel dag met haar werk, alleen, dan is sy die pragtigste mens... Maar sodra iemand anders vir haar gewas het en nou kom ek en sy is miskien nou 'n bietjie ontsteld want daai ene het so gewerk en hier kom ek nou met my (manier)...Almal se stemklank is vir haar nie te gemaklik nie want baie (van die verpleegsters) praat hard en ek praat nou maar nou saggies.

Translated N8: If I work alone with her the whole day, then she is the most beautiful person...But as soon as somebody else washed her and now I come and she is maybe a bit upset because this one worked like this and here I come with my (way)...The sound of everybody's voice isn't too comforting for her because a lot (of nurses) speak loudly and now I speak softly.

Nurse 8's statement illustrates a two-fold benefit, for the patient and nurse. It becomes evident that the patient is more comfortable being assisted by an individual nurse throughout the day. It is almost as if the patient adapts to the manners and tone of voice of an individual nurse and when there is change, it might upset the patient. An upset patient might refrain from participating in care activities or conversations, as discussed previously. This will complicate the care activities and conversations with persons with mild AD. Evidently, the nurses' duties will become increasingly more challenging, if consistency of care is disregarded with persons with mild AD. It might thus be beneficial if certain patients would be assigned to an individual nurse daily, as suggested by nurse 8.

If patients were to be assigned to nurses, the nurse-patient-ratio would need to be adequate, allowing for each nurse to divide their time fairly to their allocated patients, also permitting them to revisit the patients who might need additional care on a specific day. A nurse, who gets assigned numerous patients might not have the time to provide each patient with the individual care they might require. Thus, nurse 8's suggestion could merely become a reality if more nurses were to be employed within South African governmental homes for the elderly. Due to a lack of nursing staff, the nurses need to perform all duties, presented with at any given time, with little consideration of whose responsibility a specific patient is, at the time. The difficulty to execute nurse 8's suggestion might explain why none of the other nurses made similar suggestions.

Summary of the external nursing factors facilitating the care of persons with mild AD. Collectively, the nurses identified five external factors facilitating their care of persons with mild AD, namely patients' personality changes; reciprocity between nurses and patients can enhance the care of persons with mild AD; the peer-support between the nurses facilitating care of persons with mild AD; communication between the nurses can enhance care of persons with mild AD and the consistency of care can enhance the quality of care for persons with mild AD. Patients' personality changes were discussed in terms of patients' increasing submissiveness and the observed benefits thereof. Two nurses stated that patients' increasing submissiveness resulted in enhanced co-operation. An additional nurse stated that patients' motivation to participate in activities increased due to their increased submissiveness. By patients' increasing co-operation and motivation, activities of daily living were completed with more ease, reducing the stress experienced by nurses and their potential risk for burnout.

Five nurses discussed the benefits of reciprocity between nurses and patients and its influence on caring for persons with mild AD. The nurses established that it was of significance to identify the needs and preferences of these patients, for them to know how to handle these patients. Ultimately, it would assist the nurses to suggest appropriate activities and conversational topics for persons with AD. The nurses, who became more responsive to the patients' needs and preferences, observed an increase in patients' appreciation for them. This could lead to nurses considering their patients as being their family, improving nurse-patient relationships and which could ultimately increase nurses' job satisfaction.

Two nurses referred to the benefit of peer-support between the nurses. The support offered by fellow nurses can be viewed as a cost-effective means to facilitate care of persons with mild AD as well as enhance well-being and reduced stress in nurses. Equivalent to international studies, the current study also supports the benefit of peer-support.

Communication between nurses was not only interpreted as beneficial for peer-support but also to improve the quality of care for persons with mild AD. It was suggested by three nurses that communication across and within shifts would be beneficial. This would reduce the chances of nurses repeating tasks across shifts, unaware that they have been completed by the previous nursing shift. Repetition of tasks might reduce the quality of care persons with mild AD receive, as less time might be available for the remaining care activities. Communication across nursing shifts was however only mentioned by three nurses working in the same home for the elderly. This might be an indication that communication is particularly problematic in this specific institution.

Communication across and within shifts can additionally lead to increasing the consistency of care. One nurse suggested that consistency of care should be employed to the extent that patients should be assigned to an individual nurse daily, as the patient would become accustomed to the nurse currently working with them. Receiving care from different nurses, during the same day, might cause distress in these patients, thereby reducing their willingness to participate in conversations or activities. This does however require an improved nurse-patient ratio, which is why its execution in the South African governmental homes for the elderly might be challenging.

Interestingly, five nurses spontaneously mentioned reciprocity as enhancing the care of persons with mild AD, whereas the other external nursing factors were merely mentioned by three or less nurses.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It is of importance to establish if and which strategies the nurses employ to reduce their stress related to the challenges they might experience, in the South African governmental homes for the elderly. As discussed previously, only if the nurses are psychologically well, coping and able to remain positive, will they be able to provide optimal quality of care. The nurses might also be more receptive towards

training and assistance, related to the care of AD, when being of good psychological health themselves. Merely then would it be possible for the SLT to provide nurses with assistance with regards to the communication and cognition of persons with mild AD.

3.3) An Additional Factor *Inhibiting* the Care of Persons with Mild AD

Following the discussion of the factors facilitating the care of patients, it becomes of significance to consider the factors inhibiting the care of persons with mild AD. In addition to the challenges related to the symptoms of persons with mild AD, the nurses identified another major challenge affecting their care, namely the lack of formal training specific to AD, as evident in the following table.

Table 2-3.3: Summary of an additional factor inhibiting the care of persons with mild AD:

The lack of formal nursing training specific to AD:

- Formal and informal nursing training vs mostly self-acquired knowledge through reading and working with patients
- Focus on physical care of the patients (in South Africa)
- Importance of nursing training specific to AD

The lack of formal nursing training specific to AD. Although all nurses worked with persons with mild AD daily, merely two nurses received formal training specific to AD. Four other nurses received informal AD training sessions by occupational therapists, as will be discussed later. Nevertheless, all nurses stated that most of what they have learned about AD was by working with these patients. It became evident throughout all interviews that the nurses were more focused on the physical care of patients rather than communication with them. All nurses spoke primarily about physical care when asked about their role in the care of persons with AD. Following the discussion of physical care, the majority of the nurses mentioned some degree of emotional care. Interestingly, the majority of the nurses continued discussing physical care even when requested to provide information regarding the communication of persons with AD. The researcher attempted to ask all communication-related questions about three times per interview, in various ways, but the majority of the nurses remained unable to directly answer questions related to communication.

A reason for nurses' focus on patients' physical care could be related to their limited or lack of formal training regarding the care of persons with AD. Nurse 7 stated the following:

N7: “Ons het meer gekonsentreer op hospitale en noodopname...Is meer hier by die ouetehuse dat ek geleer het (oor AD).”

Translated N7: “We focused more on hospitals and emergency admissions... It’s more here at the old-age homes that I learned (about AD).”

The focus of hospital and emergency units is more on the physical care of patients. Nursing training, focusing primarily on the physical care of patients, is not specific to South Africa. In the United States, nurses are required to attend training sessions according to the Omnibus Budget Reconciliation Act of 1987 (Castle, 2007). However, merely 7% of the training requirements include specific AD training, the main focus being physical care. Consequently, nurses felt unprepared for specific AD care. It is thus not surprising that nurses in various studies, including the current study, primarily discussed and focussed on physical care of persons with AD. Even in homes for the elderly, the main contact nurses have with persons with mild AD is during physical care, whilst washing, dressing, grooming and feeding (Sloane et al., 2007). The nurses’ focus on the physical care of patients might also explain their continuous references to the moderate and severe stages of AD. Persons with moderate or severe AD become more dependent and consequently require additional physical care. Due to the focus of nursing training being on the physical care of patients, they might devote more time to and identify their roles as working with the persons with moderate or severe AD, thus also referring to them during the interview conducted in this study. Nurses’ primary focus on physical care illustrates the importance of training nurses with regards to care, other than physical care, specific to persons with mild AD.

This would be of utmost significance in the South African governmental homes for the elderly where nurses might be the only employed health care professionals. As these nurses need to adopt various challenging roles within these homes, it would be beneficial for nurses to attend training focussed on increasing their knowledge and preparing them with regards to AD care. As mentioned in chapter 1, nurses, who feel better trained in AD care, tend to provide better services and present with greater job-satisfaction (Grant et al., 1996; Hyer et al., 2010; Kada et al., 2009, Zimmerman et al., 2005). They feel more assured and proficient in conducting their tasks, following training sessions (Zimmerman et al., 2005). It would be valuable if the nurses in South African governmental homes would gain more self-confidence and skill in working with persons with mild AD, especially if they are the sole care providers in these homes. It was thus promising that eight nurses, who participated in the current study, acquired additional knowledge, regarding AD care, by reading appropriate literature and clinically having worked

with these patients. Evidently, these nurses aimed to empower themselves in the absence of formal training.

Summary of an additional factor inhibiting the care of persons with mild AD. The question, related to the formal training of nurses' specific to AD, revealed that the majority of the nurses have not received formal training with regards to AD. Merely, two nurses stated that they received formal training and four additional nurses mentioned informal training sessions with an occupational therapist. Similar to international nurses, the nurses in the current study focused more on the physical care of AD, even when asked about the communication of these patients. This suggests that additional nursing training might be beneficial especially due to the link between knowledge, quality of care and job-satisfaction.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. It was important for the SLT to determine the perceptions of the nurses regarding their knowledge specific to AD, as literature illustrates that nurses regularly perceive interventions as criticism to their current level of care and the individual administering the intervention programme as an intruder, with less background regarding the nursing activities (Borbasi et al., 2011; Teri et al., 2009). Thus, if the nurses feel that they have adequate knowledge regarding the care of persons with AD, they might be less receptive to training sessions with the SLT. However, the contrary was true and one nurse explicitly asked for help:

N1: We would love to help them but we have little knowledge,... not like you because you are learning about that, very specifically...Seeing that there are SLTs, who have learned about this disease - more, I think, there should be SLTs who, even if they don't come and visit the patients, but just to give a lesson about these patients...

This suggests that SLTs should be involved in training nurses to improve or maintain cognitive and communicative functions of persons with mild AD, especially in South African governmental homes for the elderly, as will become apparent in the following section.

Theme 4: The Nurses' Perceptions on the Impact of the Governmental Homes for the Elderly, in the Tygerberg District, on the Care of Persons with mild AD

As evident by the table below, the nurses' perceptions of care in the Tygerberg district homes will be discussed in terms of 4.1) reported need for additional resources and nurses to facilitate

greater care in homes for the elderly, 4.2) advantages of AD care in homes for the elderly and 4.3) disadvantages of AD care in homes for the elderly.

Table 2-4: Summary of the nurses' perceptions on the impact of the governmental homes for the elderly, in the Tygerberg district, on the care of persons with mild AD:

<p><u>4.1) Reported need for additional resources and nurses to facilitate greater care in homes for the elderly:</u></p> <ul style="list-style-type: none"> -The limited employment of other health-care professionals in the homes for the elderly -The poor nurse-patient ratio in the homes for the elderly -The request for additional resources in the homes for the elderly
<p><u>4.2) Advantages of AD care in homes for the elderly:</u></p> <ul style="list-style-type: none"> -The AD care provided by family members versus the AD care provided by nurses -Reality in South Africa: Many patients are cared for by family members
<p><u>4.3) Disadvantages of AD care in homes for the elderly:</u></p> <ul style="list-style-type: none"> - Observation that persons with mild AD deteriorated faster when put into a home for the elderly

4.1) Reported Need for Additional Resources and Nurses to Facilitate Greater Care in Homes for the Elderly

The nurses' perceptions correlated with the previously discussed literature, in reporting a need for additional resources within the governmental homes for the elderly. In chapter 1, it was mentioned that the majority of homes for the elderly in South Africa are built and run by non-governmental organisations with minimal financial support from the government (Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012). The funds provided by the government needs to be utilized for nursing salaries, building and maintenance costs of the homes for the elderly as well as patient care. The distribution of funds results in limited resources in the majority of the South African governmental homes, as evident by 4.1.1) the limited employment of other health-care professionals in the homes for the elderly, 4.1.2) the poor nurse-patient ratio in the homes for the elderly and 4.1.3) the request for additional resources in the homes for the elderly.

Table 2-4.1: Summary of the reported need for additional resources and nurses to facilitate greater care in homes for the elderly:

<p><u>4.1.1) The limited employment of other health-care professionals in the homes for the elderly:</u></p> <ul style="list-style-type: none"> -Mostly only nurses work in these homes -Occupational therapists in two of the homes and the influence thereof
<p><u>4.1.2) The poor nurse-patient ratio in homes for the elderly:</u></p> <ul style="list-style-type: none"> -Request for additional nurses to reduce the workload of the nurses
<p><u>4.1.3) The request for additional resources in the homes for the elderly:</u></p> <ul style="list-style-type: none"> -Request for shower chairs and medication for patients

4.1.1) The limited employment of other health-care professionals in the homes for the elderly. According to the nurses, only two of the five participating homes worked in collaboration with an occupational therapist, whereas none mentioned any collaborations with SLTs. Due to the minimal governmental resources in homes for the elderly it is seldom that other health care professionals other than nursing staff are employed within homes for the elderly (Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012). Another reason for mainly employing nurses might be the general shortage of other health care professionals in South Africa (Labonté et al., 2015). It is thus not surprising that merely two homes worked in collaboration with an occupational therapist. The nurses stated that in both homes, the occupational therapists obtained a part-time employment and nurses would be invited to observe the therapist performing their stimulation programmes with persons with mild AD, whenever time allowed for nursing observations. These observations would be an informal way of training nurses to perform cognitive stimulation tasks themselves. This explains why cognitive stimulation, by means of games, songs or direct exercises were merely performed in homes working in collaboration with occupational therapists. Even though the nurses provided vague reasons for conducting these exercises, they seemed to be very consistent and dedicated with the regular execution thereof. Some of the nurses, working in homes in which there was no mention of occupational therapists, seemed to have less knowledge about the cognitive deterioration of persons with mild AD. This becomes evident by means of the example below:

N2: Nou sê ek: “Haai, ek is nie net hier om vir u te was nie.” “Hoekom nurse, ek is so lief vir jou” en dan sê ek: **“Nee, jy vra elke dag dieselfde goed vir my en ek het nie meer antwoorde vir jou nie.”**

Translated N2: Now I say: “Hey, I am not only here to wash you.” “Why nurse, I love you so much” and then I say: **“No, you ask me the same things every day and I don’t have answers for you anymore.”**

The above statement shows that some nurses might not understand why persons with mild AD behave the way they do. Nurse 2 for example thought that the patient purposefully asked her the same questions all the time. She seemed to be unaware that this repetitive behaviour might be due to the patient’s cognitive deterioration. This finding is not unique to South African nurses but also nurses in eastern Sydney assumed patients’ challenging behaviour to be deliberate (Brodaty et al., 2003). In the current study, nurses’ limited knowledge was also evident concerning patients’ communication, to the point that nurse 8, for example, stated:

N8: “Ek het nogal nie gedink aan mense se praat.”

Translated N8: “I haven’t yet thought about peoples’ speaking.”

This means that in the absence of other health care professionals and with limited formal training related to AD, the nurses might be unable to successfully care for persons with mild AD in a comprehensive manner. They might misinterpret symptoms or behaviours of patients, due to a limited knowledge regarding the condition, as evident by nurse 2’s statement. Simultaneously, they would be expected to adopt all the roles, previously discussed, without any assistance or skills to do so, which might result in many additional challenges for the nurses. Consequently, the workload might be high and the nurses might feel too overwhelmed by the roles necessary for them to adopt, which might result in reduced self-confidence, in terms of their adequacy to care for persons with AD (Potgieter & Heyns, 2006) or in negative emotions towards persons with AD (Brodaty et al., 2003). Reduced self-confidence and negative emotions have been linked to a lack of job satisfaction, which might in return impact the quality of care persons with mild AD would receive. Keeping in mind the general shortage of health care professionals in the South African public health care sector (Labonté et al., 2015), it would be unrealistic to suggest for other health care professionals to seek employment in South African governmental homes for the elderly, as resources are already scarce and salaries might therefore be poor. Instead, this highlights the need for other health care professionals to provide more educational resources, workshops and additional training sessions for the nurses working in the homes for the elderly. This is in line with nurse 1’s wish:

N1: We would love to help them but we have little knowledge,...not like you because you are learning about that, very specifically...Seeing that there are SLTs, who have learned about this disease - more, I think, there should be SLTs who, even if they don't come and visit the patients, but just to give a lesson about these patients.

Funding once-off resources, workshops or training sessions would be of lower cost to the state and/or non-governmental organisations than full-time employments of various health care professionals. It would thus be more feasible to support educational resources and nursing training, thereby enhancing the quality of care persons with mild AD receive, whilst ensuring that nurses feel equipped enough to provide the best care to these patients. Quality of care can also be enhanced by an adequate nurse-patient ratio, as apparent by the nurses' perceptions below.

4.1.2) The poor nurse-patient ratio in the homes for the elderly. The limited funds further influence the care in governmental homes for the elderly, as follows:

N6: "Now if, at least we can get a lot of nurses, so that maybe on every block (there are) 4... **It's gonna be help... Gonna make it easier...** In this shift, it's only two ENAs... Now, it's very difficult."

Because of limited funds, governmental homes can only employ a small number of nurses. During the signing of the consent forms, short interviews with the managers illustrated that mainly carers are present in these homes, as their wages are less than the nurses'. However, there seem to be certain duties that mainly the nurses are allowed to perform, due to the nature of their training. According to nurse 6 and the preceding discussion in this chapter, it becomes evident that the homes are in need of additional nursing staff. These nurses experienced a real staff shortage and reported a need for an improved nurse-patient ratio. This staff shortage is not unique to the South African governmental homes but has also been recorded in other studies, for example in the United States (Castle, 2007). By improving this ratio, the nurses' workload would be reduced, potentially enhancing their overall well-being by reducing their work-related stress, leading to enhanced job satisfaction. Enhanced job satisfaction would improve the nurses' emotional, psychological and physical availability to persons with mild AD, resulting in improved quality of care (Mobily et al., 1992). Nurses' job satisfaction in governmental homes for the elderly could also be enhanced by means of additional resources, as evident by the nurses' perceptions below.

4.1.3) The request for additional resources in the homes for the elderly. The lack of financial support is not only evident in the limited staff employed in the South African governmental homes for the elderly but also by the lack of resources available for the nurses' caring tasks. For example, nurse 6 requested that they receive shower chairs, to assist with the daily washing activity, thereby increasing the time-effectiveness of the routine. Nurse 8 also requested the following:

N8: Wanneer die dokter hier kom, om vir dokter te vra: “**Kan ons nie iets gee vir- (die vergeetagtigheid)?** Want ons sien sy vergeet gou”... **Omdat dit nou mos 'n staatsplek** is het ek gevoel maar, as 'n mens oor 60 is dan wil **niemand mos meer vir jou rêrig help nie.** Want dis te veel geld.

Translated N8: When the doctor comes here, to ask the doctor: “**Can we not give something for- (the forgetfulness)?** Because we see she forgets quickly” ... **Because this is a government place,** I have the feeling, if a person is above 60 then **nobody really wants to help you anymore.** Because it is too much money.

By means of the above statement, it becomes evident that certain homes for the elderly might at times be too under-resourced for persons with mild AD to receive adequate medication. This finding correlates with the discussion in chapter 1 where it was argued that AD is not of priority in the South African health care system. According to the South African Constitution in section 27(1), every senior citizen has the right to access health care services. By not providing the patients with adequate medications, the government is not meeting their constitutional obligation towards senior citizens, with regards to health care services, as established in section 27, paragraph 2 (Borochowitz, 2011). The medication might thus remain unavailable to persons with mild AD, living in these homes. As previously discussed, even in the private sector, merely a small percentage of persons with AD receive pharmacological treatment, due to the expenses linked to the medication and the failure of some medical aids covering the costs of Alzheimer medication (Truter, 2010). This renders the costs for AD medication unaffordable for multiple patients in the private as well as government health sector. The lack of medical treatment for persons with mild AD could be evaluated as distributive injustice, as these might be patients who have contributed to society by means of employment and their social engagement for years, who might be able to maintain their functions and quality of life for longer periods of time, if they were to be given adequate medication. It should not be the reality that patients cannot receive sufficient quality of care, due to a lack of resources, in an environment that was established to care for them. The lack of financial resources explains why the majority of homes for the elderly in South Africa are built by non-governmental

organisations (Neighbourhood Old Age Homes – STTOP: Housing and Health Care for the Elderly, 2012) and most of South Africa's AD care and caregiver training is provided by non-governmental organisations (De Jager et al., 2015).

Summary of the reported need for additional resources and nurses to facilitate greater care in the homes for the elderly. The nurses in the homes for the elderly confirmed the lack of resources discussed in literature. They stated that hardly any other health care professionals but themselves work in homes for the elderly. Only two homes worked in collaboration with an occupational therapist employed part-time at the homes, leaving the nurses to complete the stimulation tasks when occupational therapists were elsewhere. The nurses, in the remaining homes, would be required to always assume the roles of an occupational therapist, even though they might have received limited or no training with regards to the appropriate stimulation tasks. This highlighted the need for additional training by other health care professionals, to increase nurses' job satisfaction, by providing skills and assisting the nurses in their roles.

Another resource, identified by one nurse, for an improved nurse-patient ratio within the homes aimed at reducing the workload of the current staff and thereby increase the nurses' job satisfaction.

Additionally, two nurses requested that more resources should be present in the homes for the elderly, in the form of shower chairs and medication. It should not be the reality that patients cannot receive sufficient quality of care, due to a lack of resources, in an environment that was established to care for them.

The overall findings illustrated a perception among the participants of a lack of resources in the South African governmental homes for the elderly. These findings should advocate for fellow health care professionals to assist nurses, working in South African governmental homes for the elderly, to acquire more skills and knowledge related to the multiple roles they adopt in the AD care. These resources, workshops and/or training sessions should be funded by the state and/or non-governmental organisations.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. The above-mentioned highlights the need for SLTs to provide more educational resources, workshops and additional training sessions for the nurses working in the homes for the elderly. An SLT might not have the financial means to solve the poor nurse-patient ratio and provide the nurses with additional resources (e.g. shower chairs), but they should share their knowledge and train the nurses with regards to the communication and cognition of persons with mild AD. This would be beneficial to the well-being of the nurses and the patients. Upon termination of my research and consideration of the above-mentioned findings, I felt it was my obligation, as researcher, to provide the homes with a basic educational pamphlet and video discussing communication and cognition, as will be discussed in the implication section.

4.2) Advantages of AD Care in Homes for the Elderly

Even though the care of persons with mild AD might be challenging in the South African governmental homes for the elderly due to the lack of resources, nurse 1 identified many advantages to caring for these patients in the homes, as evident by the table below.

Table 2-4.2: Summary of the advantages of AD care in homes for the elderly:

- The AD care provided by family members versus the AD care provided by nurses
- Reality in South Africa: Many patients are cared for by family members

Nurse 1 stated that persons with AD should be cared for in homes for the elderly, for the following reasons:

N1: I think you need to take him away from the family... and keep him in the home, where he will get people who understand him. Cause even in the family, maybe one that is closer to him, will understand him, not the entire family... I am speaking from my own perspective cause we have big families in the house... So there would be one person maybe, who is closer to him, who has that patience towards him. But some of the members of the family will not endure with him... In a nursing home there are professionals, there are people..., who maybe have experienced staying with a patient like that and... they are paid to do the job... They need to look after him.

Nurse 1 noted valid reasons for persons with mild AD to be cared for in homes. She stated that families might have limited understanding about the condition, and might thus lack the patience necessary for caring for persons with mild AD. She also elaborated by saying that the nurses

are paid to take care of these patients and might have more experience regarding the condition, due to prior exposure to AD, making homes thus the better housing option for persons with mild AD. As discussed in chapter 1, this is however not the reality in South Africa. In Cape Town 79% of patients, attending a memory clinic, are taken care of by family members (De Jager et al., 2015). Merely 2% of senior citizens requiring 24-hour nursing care, are accommodated for (De Jager et al., 2015). Persons with AD have minimal access to their right to adequate housing, as established in the South African Constitution in section 26 (Borochowitz, 2011) and thus even though nurse 1 provides good reasons for placing these persons with AD in homes for the elderly, most will remain at home with family members, and in many cases to the detriment of the person with AD as well as many of his/her family members.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. Nurse 1's statement is promising as it reveals her faith in the homes for the elderly as best option for persons with mild AD. Her faith in the homes might lead to her aiming to provide the best quality of care to these patients, as this would be their best caretaking option. Nursing attitudes like the above-mentioned are favourable to the SLT, as they might enhance nurses' openness to receive assistance from other health care professionals, to improve their quality of care.

4.3) Disadvantages of AD Care in Homes for the Elderly:

According to nurse 8, the care of persons with mild AD in the governmental homes for the elderly does not include advantages only, but also creates challenges. It was observed that persons with mild AD deteriorated faster when put into a home for the elderly, as apparent by the following table.

Table 2-4.3: Summary of the disadvantages of AD care in homes for the elderly:

-Observation that persons with mild AD deteriorated faster when put into a home for the elderly

Nurse 8 observed the following:

N8: Die mense wat van buite af kom,...wie se Alzheimer's nog nie so erg is nie, in die beginstadium is,...**hulle gaan dan vinniger in daai vergeet area** want hulle moet daar hard konsentreer. Ek moet nou alles doen vir myself...Dit het ek ervaar met mense wat

van buite af kom... Hulle moet nou hier kom en **die aanpassing is baie moeilik en hulle gaan dan vinnig agteruit.**

Translated N8: The people that come in from outside..., whose Alzheimer's is not so severe, in the beginning stage,... **then they move quicker into the forgetful area,** because they must concentrate hard there. Now, I must do everything for myself... This was my experience with people that came from outside. Now they must come here and **the adjustment is very difficult and they regress quickly.**

No literature was found to support this observation. It is however of such significance that if found to be a general phenomenon in South African homes, adaptations in homes are necessary, to address the deterioration of persons with mild AD.

Implication and relevance of these findings to SLTs directly or indirectly involved in the care of institutionalised elderly persons. If the above finding would be established as a general phenomenon in some of the homes for the elderly, it would be of importance to determine the reasons for patients' deterioration. Should one of the reasons be that these patients receive limited stimulation, thereby reducing blood flow to their frontal lobe and potentially allowing for faster deterioration, it would be the SLT's role to provide adequate stimulation programmes to nurses to target patients' deterioration.

Concluding this chapter, it becomes evident that the nurses perceive persons with mild AD to undergo multiple behavioural changes due to motor, perceptual, cognitive, communicative and emotional deterioration as well as personality changes. The nurses interpreted these behavioural changes as beneficial and/or challenging when caring for persons with mild AD. The nurses need to support patients through all these changes and thereby assume multiple roles of care in various spheres of patients' lives. All these care activities are performed within the governmental homes for the elderly, within the Tygerberg district. This environment comes with its own challenges and benefits, as previously explained by the nurses. Some implications and limitations of the findings that were presented in this chapter are identified and elaborated on in chapter 4.

Chapter 4: Implications and Limitations

The implications of this study are based on the research findings and will be elaborated on within 5 main categories, namely 1) the care of persons with AD in South African governmental homes for the elderly, 2) nurses' well-being in South African governmental homes for the elderly, 3) the need for additional training, 4) SLT's development of a basic educational pamphlet and a video discussing cognitive and communicative stimulation for persons with mild AD in the Tygerberg district and 5) areas to investigate in future research.

1) The Care of AD in South African Governmental Homes for the Elderly

The nurses in the homes for the elderly confirmed the lack of resources discussed in literature. It is evident that hardly any other health care professionals but themselves work in homes for the elderly, leaving the nurses with multiple and varied roles to fulfil. The nurses seem to regularly lack the broad range of skills and knowledge to adequately realise these multi-faceted roles. Furthermore, the nurse-patient ratio within the homes seems poor and nurses indicated a need for more resources in the homes for the elderly, specifically shower chairs and medication for the patients. The overall findings illustrate a lack of resources in the South African governmental homes for the elderly. These findings have provided insight into the need for fellow health care professionals to assist nurses, working in South African governmental homes for the elderly, to acquire more skills and knowledge related to the multiple roles they adopt in the AD care. This might improve the quality of care for persons with AD and it might be a means to increase nurses' job satisfaction, in the absence of additional resources and an improved nurse-patient ratio. Ideally, external funding for homes for the elderly would be beneficial, thereby providing them with the financial means for additional resources and nurses.

2) Nurses' Well-Being in South African Governmental Homes for the Elderly

Nurses, in the South African governmental homes for the elderly, are regularly the sole health care professionals, assisted by carers. It is of significance to care for their well-being, as they adopt multi-faceted roles in caring for persons with AD. These roles were perceived as extremely challenging by the majority of the nurses. The nurses seemed to be able to cope with their work-environment due to their hardy personalities (strengthened by their empathy, patience and tolerance) and seeing AD care as a learning opportunity for taking care of their own parents in old age. Other strategies, which enhanced nurses' coping, included patients'

personality changes which facilitated the care of persons with mild AD, the reciprocity between nurses and patients, the peer-support between the nurses, the communication between the nurses enhancing care of persons with mild AD and the consistency of care enhancing the quality of AD care.

It was of significance to determine the strategies that the nurses employ to reduce their stress resulting from the challenges related to caring for patients with AD. These could be points of departure in the development of training programmes, specific to South African nurses. If these strategies were to be compared to evidence-based guidelines, a list of potential (and proven) helpful coping strategies could be drawn up and distributed for support and consideration by nurses working in governmental homes for the elderly throughout the Province and country. Thereby effective strategies and means of execution could be found, increasing the likelihood for nurses to remain psychologically stable and positive. Their psychological health would thus positively influence their quality of care for persons with mild AD. This would enhance patients' and nurses' well-being. Additionally, the nurses might also be more open towards receiving training and assistance, related to the care of AD, when being of good psychological health themselves.

3) The Need for Additional Training

It became evident throughout all interviews that the nurses are more focused on the moderate to severe stage of AD. It might be that their role, working with persons with moderate or severe AD, is more apparent to them than their role related to mild AD. This might be due to the fact that persons with moderate or severe AD become increasingly more dependent and require additional help in all care activities, including physical care, which nurses seemed to be better trained at. This became apparent by the nurses' focus in the interviews on the physical care of patients rather than their communication. All nurses spoke primarily about physical care, when asked what their role entailed in the care of persons with AD. The majority of the nurses continued discussing physical care even when they were requested to provide information regarding the communication of persons with AD. Thus, the nurses' training focus on physical care and increasing need for persons with moderate or severe AD to receive physical care, might explain the nurses continuous reference to the later stages of the condition.

Although the nurses collectively identified a range of communicative and cognitive strategies to employ with persons with mild AD, each individual nurse made reference to limited

strategies, thereby illustrating a rather incomplete knowledge base. This was further illustrated by their difficulty to provide reasons for employing certain strategies. The nurses, who worked in collaboration with an occupational therapist, seemed to be more aware about memory stimulation techniques but also only provided vague reasons for employing those techniques. The increased awareness of certain strategies through collaboration with an occupational therapist, illustrates the importance for fellow health care professional to assist nurses, working in South African governmental homes for the elderly, to acquire more skills and knowledge related to the multiple roles they adopt in the AD care, other than physical care. Supplementary it would be beneficial if a short and basic training course on caring for persons with mild AD can be developed, with input from the various and relevant health care professionals, and that it be a requirement that nurses complete the course successfully, before being able to work in homes for the elderly. The state should invest in the development, presentation and administration of such a course. Any form of training programme should focus on the emotional, cognitive and communicative care of these patients. Following all of the above and the completion of my research, I felt it was my obligation, as researcher, to provide the homes with a basic educational pamphlet and video on communication and cognition, as discussed below.

4) Development of a Basic Educational Pamphlet and Video on Cognitive and Communicative Stimulation for Persons with mild AD in the Tygerberg District

The explicit request by nurse 1 and the evidence that resources might be limited in governmental homes, resulted in the development of short and basic educational material in the form of a pamphlet and a video (please refer to appendix 4 for the pamphlet). The cognitive and communication stimulation information is based on nurses' needs as was identified in the results of this study. It addresses nurses' perceptions regarding the communication and cognition of persons with mild AD. It aimed to provide basic strategies to improving or maintaining the communicative and cognitive abilities of persons with mild AD for longer periods of time. The strategies aimed to promote communication and cognition during daily care of persons with AD and would thus not require more time from the nurses. Practical means to successfully employ the strategies, were modelled to the nurses in the accompanying video. The video has been distributed to the nurses and managers of the participating homes for the elderly and is available in English and Afrikaans. The pamphlet is however not only designed for the nurses but also for carers as well as family members. To make the pamphlet more accessible, it has been translated into Afrikaans and English.

5) Implications for Future Research:

Following the completion of this study, findings support future research to focus on the deterioration of persons with mild AD following their admission to governmental homes for the elderly. It would be of interest to determine why and if it is the norm that upon admission to governmental homes, progression of the condition is more rapid. Ideally, one would like to eliminate factors within homes that might accelerate progression of AD. Another research topic of interest in these homes would include the relationship between job satisfaction and psychological support of these nurses within the Tygerberg district. It would be of significance to determine to what extent external psychological support might be available to these nurses working in specified homes. Additionally, it would be of interest to compare the coping strategies identified by nurses against evidence-based guidelines, to draw up potential (and proven) helpful coping strategies, which could be distributed for consideration by nurses working in governmental homes for the elderly throughout the Province and country. Furthermore, it would be of relevance to identify the extent of communication between and across nursing shifts and its related benefits and challenges. Another recommendation for future research could be comparing a nurse with more qualifications to an ENA, thereby identifying how their perceptions towards persons with AD match and/or differ. Additionally, it would also be of value to develop, implement and evaluate a multidisciplinary short training course for nurses on caring in a comprehensive manner for persons with mild AD within homes for the elderly. Thereby using the findings of this study to influence the content of such a course, especially as far as the stimulation of communication and cognition of persons with mild AD is concerned. Lastly, it would be interesting to test the effectiveness of the educational pamphlet and video, developed following this study, discussing the cognitive and communicative stimulation of persons with mild AD based on the nurses' needs, working within the governmental homes in the Tygerberg district.

Limitations of the Study:

Nine limitations were noted during the completion of this study. The first main limitation is the participation of five instead of seven proposed homes for the elderly. Additionally, the researcher was unable to interview all night-shift nurses, as it was unsafe for her to enter the research area beyond 4pm. This study was thus completed with 12 participants (only 2 night-shift nurses), unable to reach data saturation.

Although all nurses had the same formal nursing education, as controlled for by this study, by only including enrolled auxiliary nurses, some had received additional training within the homes they are employed in. These informal training sessions included nursing observations during therapy sessions between occupational therapists and persons with mild AD. These observations might have influenced the perceptions of nurses related to the care of persons with mild AD. The heterogeneity of nurses' responses could thus have been the result of additional training instead of different nursing experiences specific to persons with mild AD.

It could be argued that choosing enrolled auxiliary nurses as study participants is a third limitation. As previously mentioned, these nurses undergo 44 weeks of training, after which they are allowed to practise as nurse. Nurses with additional training, such as enrolled or registered nurses, would possibly be able to provide more insight in terms of AD, which would have changed the results of the study. However, the researcher consciously and purposefully chose enrolled auxiliary nurses as study participants, as they rendered the greatest number of nurses in the five homes for the elderly.

A fourth limitation included the use of convenience sampling. The problem around convenience sampling is that it might not be representative of the entire population, increasing the risk of including outliers and generalising their perceptions to the study population. This study can therefore be seen as representing the perceptions of 12 enrolled auxiliary nurses working within five of the governmental homes for the elderly, situated in the Tygerberg district within the Western Cape province of South Africa.

A fifth limitation was the volunteer effect. Nurses could choose to participate and it is therefore possible that nurses who refrained from participating would have provided additional heterogeneity to the answers. This is based on the belief that a nurse who refrained from participating might be inherently distinct from the nurses who participated in the study. Their differences in character, knowledge or skills might have influenced their participation within the research study (Salkind, 2010). The two nurses, who refrained from participating within this research, indicated that they felt too unprepared with regards to their AD knowledge to participate in the study.

The definition of mild AD, as it was provided to the nurses, might be seen and evaluated as insufficient and as limitation to this study. Mild AD was defined as the beginning stage of the

disease, usually shortly after diagnosis. Due to the nature of the phenomenological research design, it was impossible for the researcher to provide a rich definition of mild AD, as any indication of symptoms or level of dependence could have influenced the nurses' perceptions. The researcher would thus have probed certain information, thereby possibly altering the nurses' responses. As it was of utmost importance to the researcher to truly determine the nurses' lived experiences and perceptions without any impositions or preconceptions, she decided against an extensive definition of mild AD.

Another limitation included the lack of availability of a quiet space for ideal audio-recordings. Due to the lack of resources in homes, only two homes were able to provide an environment optimal for audio-recordings. In the remaining three homes, interviews had to be terminated until quietness was re-established or residents and other nurses, disrupting the interview, left the room again. The interviews were resumed shortly after. A disruption in an interview might have altered nurses' responses. For example, elaborations, provided at the time of excessive background noise, were regularly not resumed following the disruptions.

The eighth limitation involved two nurses and their reaction to the researcher. It seemed as they might previously have had a negative experience with researchers, which initially reduced their willingness to speak to the researcher, although they provided consent to participate in the study. One of the two nurses stated that it is "yet again just another researcher testing her knowledge". Initially, their misperceptions of researchers might have altered their responses in the interview. However, shortly after commencing with the interviews, the researcher felt that she was able to gain their trust and that the interviews were completed successfully.

Another limitation could have been that the researcher's understanding and interpretation of a few individual participants' perceptions were merely discussed with them during the member-checking process and not with fellow researchers or supervisors. This might have influenced the interpretation and report of the research findings.

Chapter 5: Conclusion

Considering the increasing aging population, the characteristics of the AD condition, AD in South Africa, the possibilities and challenges related to nursing interventions as well as the identified importance of cognitive and communicative stimulation of persons with mild AD, a definite need existed for the current study to be conducted. As evident by existing literature and the findings of this study, persons with mild AD present with multiple symptoms in motor, memory, cognitive, communicative and emotional domains. This study discussed the perceptions of nurses regarding the maintenance and/or deterioration of motor functions in persons with mild AD and evaluated the motor functions in terms of patients reduced cognitive functions. With regards to patients' memory, all the nurses stated that persons with mild AD presented with short-term memory deficits whereas the long-term episodic memory was mostly maintained. The majority of patients seemed to primarily speak about personal past experiences, referring to them as if they currently occurred in the present. The nurses observed cognitive deficits in persons with mild AD, namely the tendency of persons with mild AD to create their own world, their limitations in executive functioning, more specifically patients' deficits in cognitive flexibility, reasoning and problem-solving and their increasing disorientation in time and place. According to the nurses, environmental disorientation is aggravated by their admission to the homes for the elderly or/and when environmental changes in the homes occurred. All nurses perceived the communication changes as extremely challenging. The nurses reported that persons with mild AD presented with changes in language production, comprehension and speech motor abilities. Emotional and personality changes were discussed by the nurses in terms of persons with mild AD assuming more child-like characteristics and behaviours, becoming more aggressive, their desire to initially remain independent and their tendency to become more depressed.

As nurses are often the sole healthcare providers in the South African governmental homes for the elderly, they are required to assist persons with mild AD in all of the above-mentioned domains, thereby adopting multi-faceted roles. The nurses discussed their roles in terms of the physical, memory, communicative and emotional care of persons with mild AD. Physical care was discussed in terms of providing medication, assisting with self-care activities, as well as walking with these patients. Memory exercises provided to the patients by the nurses were mentioned in terms of direct or/and indirect exercises, stimulating recall and entertaining persons with mild AD. Patient care specific to communication included strategies in five main

domains, namely language adaptation, adaptation of speech output, strategies assisting with memory and cognitive limitations as a means to improve communication and the importance of a positive mood to improve communication. The nurses realised that patients' communication will be improved by regularly employing the facilitative strategies and simultaneously reducing the inhibiting factors. As a collective, the nurses identified many different strategies. However, most of the individual strategies were merely mentioned by one or two of the nurses. A good relationship with persons with mild AD was seen as a foundation to emotional care, to keep patients happy, comforted and calm by providing them with person-centered care, consolation and security, as well as loving and caring for them in emotional states, whilst identifying their moods and reasons for their emotional states.

The nurses experienced various challenges related to the symptoms of persons with mild AD and their roles they were expected to assume. These challenges were exacerbated by nurses' lack of formal training related to AD specific care, with the focus of training being on physical care. It was thus not surprising that the nurses spoke primarily about physical care, when asked what their role entailed in the care of persons with mild AD. The majority of the nurses continued discussing physical care even when they were requested to provide information regarding the communication of persons with mild AD.

The challenges related to the care of persons with mild AD were further amplified by the minimal funds available for the care of senior citizens, including persons with AD, in South Africa. Minimal funding for governmental homes for the elderly led to nurses often being the only health care professionals working at these homes. However, the restricted funds in these homes merely allowed for the employment of a small number of nurses, the remaining staff being carers. Limited resources, poor nurse-patient ratios and the absence of health-care professionals in South African governmental homes for the elderly, increased the workload and work-related stress experienced by the nurses.

Strategies, which assisted the nurses in coping with these challenges, included their personalities (their empathy, patience and tolerance), discussed as a hardy personality in literature and their perception that caring for persons with mild AD was a learning opportunity for assisting their own parents, thereby demonstrating cognitive appraisal. Other coping strategies mentioned by nurses comprised of some of the patients' personality changes improving the care of persons with mild AD, the reciprocity between nurses and patients, the

peer-support between the nurses, the communication between the nurses which enhanced the consistency and quality of care of persons with mild AD. These strategies were however only mentioned by a few nurses. It would be beneficial if coping strategies were to be advocated for and employed by all nurses in each governmental home for the elderly, possibly providing means for managing the stress related to the challenges of AD care and keeping nurses psychologically stable and positive.

Following this research, it became evident that the nursing staff, in these homes, is well positioned to provide interventions to persons with mild AD, as they were already adopting many roles in AD care (i.e. physical, memory, cognitive, communicative and emotional care). It should however not be assumed that the nurses would be able to cope with additional roles, as they are already facing many challenges to complete their roles, especially the roles for which they have received limited training. These findings could advocate for fellow health care professionals in assisting nurses, working in South African governmental homes for the elderly, to acquire more skill and knowledge related to the multiple roles they adopt in AD care. This could improve the quality of care for persons with AD and it could be a means to increase nurses' job satisfaction, in the absence of additional resources and an improved nurse-patient ratio. It would be beneficial to the care of patients and nurses to provide nurses with skills, supplementing their current roles, thereby enhancing or maintaining patients' functioning, whilst nurses' workload remains constant.

The relevance of this research to a SLT becomes evident in view of the SLT's role in providing cognitive and communicative interventions to all individuals requiring assistance, including persons with mild AD. The absence of SLTs in South African governmental homes for the elderly highlights the importance of SLTs to assist the nursing staff in providing cognitive and communicative interventions to persons with mild AD, as nurses seemed to have had limited to no exposure to interventions that directly or indirectly targeted cognition and/or communication. The nurses established a need for such interventions as the majority of them admitted that they struggled to communicate with persons with mild AD and some even thought that there was nothing one can do to help these patients. Following the findings of this study, it became apparent that the perceptions of the nurses show the need for the development, presentation and administration of cognitive and communicative training interventions, aimed at the nurses working in governmental homes in the Tygerberg district (Cape Town, Western

Cape). These interventions would require focussing on cognitive and communicative stimulations during daily care activities, thereby supplementing patients' care activities with additional stimulation, without creating additional work for the nurses.

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Appendices:

Appendix 1 (a): English Semi-Structured Interview

Date:

Duration of interview:

Home:

Participant number:

Introduction:

“I would like to talk about your experience with elderly persons with mild Alzheimer’s dementia. I will ask you questions to find out how you feel about their communication (the way they speak and understand) and cognition (the way they think and remember). There are no right or wrong answers, so please feel free to answer according to your experience. As you know, I will record our conversation so that I do not lose any of the information you share with me. Do you have any questions for me before we start?”

Please tell me about what you learned about Alzheimer’s dementia during your nursing education?

In the course of your nursing work at xxx-institution, how often do you need to take care of persons who are in the early stages of Alzheimer’s dementia?

What do you think is the nurse’s role in caring for a patient in the early stages of Alzheimer’s dementia (within the context of a home for the elderly)?

Is it part of your role to help patients with their communication and cognitive problems?

Who do you think should help patients with early stage Alzheimer’s dementia with their communication and cognition problems?

Please tell me about your experience of caring for persons in the early stage of the Alzheimer's dementia condition.

What aspects of caring do you find easier, in the early stages of Alzheimer's dementia?

What is most difficult for you in caring for Alzheimer's dementia patients, in the early stages of the condition?

In your experience, what are the major problems that Alzheimer's dementia patients are struggling with, in the early stages of the condition?

Please tell me about your experience of communicating with patients with mild Alzheimer's dementia.

What aspects of communication with a patient with early stage Alzheimer's dementia do you find easier?

What aspects of communication with a patient with early stage Alzheimer's dementia is difficult for you?

If you think back to your interactions with early stage Alzheimer's dementia patients, how would you describe their reaction when you spoke to them?

What do you think can help these patients to understand when somebody is speaking to them?

Do you think that there are certain things that may confuse patients with early stage Alzheimer's dementia when somebody speaks to them?

In your experience, what might confuse patients with Alzheimer's dementia when somebody speaks to them?

Patients with Alzheimer's dementia have problems with their cognition, in other words with their way of thinking, solving problems and remembering.

Please tell me about the problems in cognition that have you noticed in persons with early stage Alzheimer's dementia?

Appendix 1 (b): Afrikaans Semi-Structured Interview

Datum:

Tydsplan van onderhoud:

Ouethuis:

Deelnemer nommer:

Inleiding:

"Ek wil graag met u praat oor u ondervinding met persone met geringe Alzheimer se demensie (AD). Ek sal u vrae vra om vas te stel hoe u voel oor hulle kommunikasie (die manier van praat/gesels en verstaan) en hulle kennis (die manier van dink, probleem oplossing en onthou). Daar is geen regte of verkeerde antwoorde nie, so voel asseblief vry om te antwoord volgens u eie ervaring. Soos u weet sal ek vir navorsing doeleindes u antwoorde opneem, sodat ek nie waardevolle inligting verloor nie. Het u enige vrae vir my voordat ons begin? "

Asseblief vertel vir my, wat u oor AD geleer het, tydens u verpleegster opvoeding?

In die loop van u verpleging werk by xxx-instansie, hoe gereeld versorg u AD pasiënte, in die aanvangfase van die kondisie?

Wat dink u is u rol, as verpleegster, tydens die versorging van 'n persoon met AD (in 'n ouetehuis konteks)?

Is dit deel van u rol om pasiënte met hulle kommunikasie en kennis probleme te help?

Wie dink u moet pasiënte met hulle kommunikasie en kennis tydens die aanvangfase van AD help?

Asseblief vertel vir my van u ervaring oor die versorging van persone met geringe AD.

Watter aspekte van versorging ervaar u as makliker, in die aanvangfase van AD?

Wat ervaar u as moeilik oor die versorging van AD pasiënte, in die aanvangfase van die kondisie?

In u ervaring, wat is die hoof bekommernisse waarmee AD pasiënte sukkel, in die aanvangfase van die kondisie?

Asseblief vertel vir my van u ervaring oor kommunikasie met pasiënte met geringe AD.

Watter aspekte van kommunikasie ervaar u as makliker wanneer u met 'n pasiënt in die aanvangfase van AD kommunikeer?

Watter aspekte van kommunikasie ervaar u as moeilik wanneer u met 'n pasiënt in die aanvangfase van AD kommunikeer?

As u terug dink na 'n gesprek met pasiënte in die aanvangfase van AD, hoe sou u die pasiënte se reaksie beskryf as u met hulle praat?

Wat help die pasiënte om beter te verstaan wanneer mense met hulle praat?

Dink u daar is sommige goed wat pasiënte in die aanvangfase van AD verwar as mense met hulle gesels?

In u ervaring, wat dink u kan pasiënte met AD verwar as mense met hulle gesels?

Sou u sê dat die kognisie (denkwyse, probleem oplossing en manier van onthou) van pasiënte met AD verander, van voor hulle siek is tot hulle geringe AD kry?

Asseblief vertel vir my oor die kognitiewe probleme van pasiënte in die aanvangfase van AD wat u al agtergekom het?

Appendix 2 (a): English Biographical Questionnaires

Name:

Home language:

Participant number:

Fluent in:

English	
Afrikaans	

What nursing education did you receive?

Registered nurses	
Enrolled nurses	
Enrolled auxiliary nurses	
Student auxiliary nurses	

How long have you worked with persons with **mild** Alzheimer's dementia:

0 - 1 year	
1 year – 5 years	
5 years and more	

Appendix 2 (b): Afrikaans Biographical Questionnaires

Naam:

Huistaal:

Deelnemer nommer:

Vlot sprekend in:

Engels	
Afrikaans	

Watter verpleegster opvoeding het u ontvang?

Geregistreerde verpleegsters	
Ingeskrewe verpleegsters (Enrolled nurses)	
Ingeskrewe aanvullende verpleegster (Enrolled auxiliary nurses)	
Student aanvullende verpleegster (Student auxiliary nurses)	

Hoe lank het u al gewerk met mense met **geringe** Alzheimer se demensie:

0 - 1 jaar	
1 jaar – 5 jare	
5 jare en meer	

Appendix 3 (a): English Informed Consent for the Managers of the Homes for the Elderly

TITLE OF THE RESEARCH PROJECT:

The perceptions of nurses regarding the communication and cognition of persons with mild Alzheimer's dementia, within the Tygerberg district of Cape Town

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: *Corinna Jeske*

ADDRESS: *Division of Speech, Language and Hearing Therapy, Faculty of Medicine and Health Science, Stellenbosch University, Tygerberg*

CONTACT NUMBER: *0723108949*

Your old-age home has been chosen to take part in a research project. Please take some time to read the information presented below, which will explain the details of this project. Please ask the researcher any questions about any section of this information that you do not fully understand. It is very important that you have a thorough understanding about what this research entails and how the Alzheimer's dementia nurses, in your old-age home, could be involved. Also, participation is **entirely voluntary**. If participation is declined, this will not affect the participant negatively in any way whatsoever.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

Literature shows that the number of Alzheimer's dementia patients is raising. In South Africa, there is up to date little financial support for Alzheimer's dementia from the government. Due to minimal financial support from the government, persons with Alzheimer's dementia are rarely seen by therapists. Therapists could help patients maintain many of their skills for longer periods of time. For example, speaking exercises could help patients to remain speaking for years instead of months.

Therefore, given the increasing number of persons with Alzheimer's dementia and the minimal health care funding for the senior citizens in South Africa, the speech-, and language therapist's role includes motivating for and participating in the design of nursing programmes. Nursing programmes designed by speech-, and language therapists would be focused on cognitive (the way patients think and remember) and communicative (the way patients speak and understand) stimulation for persons with mild Alzheimer's dementia. Literature indicates that nursing interventions have been applied internationally, with direct or indirect focus on communicative

and cognitive stimulation. However, these interventions might not be applicable in a country as culturally diverse as South Africa. In order to design training interventions aimed at nurses working in the Tygerberg district (Cape Town, Western Cape), it would first be necessary to find out what the perceptions of the nursing staff is with regards to the cognition and communication of persons with mild Alzheimer's dementia. This South African study thus aims to determine the perceptions of a group of nurses regarding the treatment of Alzheimer's dementia, with specific reference to the communication and cognitive abilities of these patients.

The above-mentioned aim will be achieved through the use of interviews. 7 governmental old-age homes, within the Tygerberg district (Cape Town), will be asked to participate in the study. All home nurses, who have worked with Alzheimer's dementia patients and are willing to participate in the study, will be interviewed in each of the corresponding homes. The information provided by the nurses will remain anonymous.

Why has your old-age home been invited to participate?

This study focuses on governmental old-age homes. Your home fits the criteria of this research study and is thus invited to participate.

What are the study procedures? What will the participants be asked to do?

- If the nurses agree to take part in the study, it will involve their participation in individual interviews. Approximately 45 minutes will be needed to complete an interview. The interviews will be scheduled so that it does not affect the care of the elderly home residents.
- The time and venue of the interviews will be arranged at the nurses' convenience. The venue has to allow for the interviews to be appropriately conducted and for audio-recording thereof.
- The questionnaire used in the interviews contains several questions about the nurses' experiences during their work at the old-age home. More specifically, the questions will focus on the communication (the way patients speak and understand) and cognition (the way patients think and remember) of persons with early stage Alzheimer's dementia.
- The content of the nurses' interviews will be confidential. Their name will not appear on any record. The nurses will receive a number to identify their interviews. Their identity will remain anonymous and will not be used in any publication of the study results.
- With the nurses' permission, we would like to audio-record the interviews. It will later be transcribed for the purposes of analysis. Their name will not appear on the transcriptions. The researcher will do the analysis of the interviews.

Will the participants benefit from taking part in this research?

The information that is obtained in this study may be useful in making possible adjustments to the interprofessional learning opportunities arranged at the old-age homes to enhance the training of nurses and thereby benefit the care of the patients. There are no direct benefits to the nurses for participating in this study.

Are there any risks involved in participating in this research?

There are no risks involved in taking part in this research and participation is completely voluntary.

Can the participants stop being in the study and what are their rights?

The nurses do not have to be in this study if they do not want to. If they agree to be in the study, but later change their mind, they may drop out at any time. There are no penalties or consequences of any kind if the nurses decide that they do not want to participate.

Who will have access to the information obtained during the interviews?

- You are hereby promised that all personal information that the nurses give will remain confidential, or will be disclosed only with their permission.
- All recordings will not be released to any persons or entities other than the researcher of Stellenbosch University. The recordings will be destroyed within 6 months of completion of nurses' involvement in the study. Until they are destroyed they will be stored in a password protected computer file to which only the researcher has access.
- The anonymous scientific data in which no individuals will be named or identified, resulting from the study, may be presented at meetings and published so that the information can be useful to others.
- Collected data will be stored on computer files that will be protected by a password known only to the researcher.

Will the participants be paid to take part in this study and are there any costs involved?

No, the participants will not be paid to take part in the study and there will be no costs involved if they do decide to take part.

Is there anything else that you would like to know?

- You can contact Corinna Jeske at 072-310-8949, if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938-9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- If requested, you can receive a copy of this information and consent form for your own records.

Declaration by manager

By signing below, I agree for the research study to take place in(name of old-age home).

.

I declare that:

- I have read/have been read this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.

Signed at (*place*) on (*date*) 2016.

.....
Signature of manager

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took suitable time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) on (*date*) 2016.

.....
Signature of investigator

.....
Signature of witness

Appendix 3 (b): Afrikaans Informed Consent for the Managers of the Homes for the Elderly

TITEL VAN DIE NAVORSINGSPROJEK:

Die persepsies van verpleegsters oor die kommunikasie en kognisie van persone met geringe Alzheimer se demensie, in die Tygerberg distrik in Kaapstad

VERWYSINGSNOMMER:

HOOFNAVORSER: *Corinna Jeske*

ADRES: *Spraak-, Taal-, en Gehoortherapie Afdeling, Fakulteit Geneeskunde en Gesondheidswetenskappe, Universiteit van Stellenbosch, Tygerberg.*

KONTAKNOMMER: 0723108949

U ouetehuis is gekies om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die besonderhede van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorser daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u Alzheimer se demensie versorgers daarby betrokke kan wees. Deelname is **volkome vrywillig**. Die versorgers in u ouetehuis wat verkies om nie deel te neem in hierdie studie nie, sal op geen wyse hoegenaamd negatief beïnvloed word nie.

Hierdie navorsingsprojek is deur die **Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch** goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

Literatuur wys dat die getalle van Alzheimer se demensie pasiënte toeneem. Tot vandag, word net minimale finansiële ondersteuning van die Suid Afrikaanse regering gebied, wat die versorging van Alzheimer se demensie pasiënte betref. Beperkte finansies belemmer dat Alzheimer se demensie pasiënte gereeld gesien kan word deur terapeute. Terapeute kan vir die pasiënte help om vaardighede vir langer periodes te hou. By voorbeeld, deur spraak oefeninge kan die pasiënt miskien nog vir jare praat in plaas van net 'n paar maande. Dit sou dus voordelig wees om verpleegsters vaardighede aan te leer, sodat hulle die terapeute kan word en die Alzheimer se demensie pasiënte kan help met hulle kommunikasie (die wyse van praat) en kognisie (die wyse van denk). Om 'n suksesvolle intervensieprogram te ontwerp, het hierdie studie ten doel om die persepsies van verpleegsters in verband met die behandeling van Alzheimer se demensie te bepaal, met spesifieke verwysing na die kommunikasie en kognitiewe vermoëns van hierdie pasiënte.

Gegewe die toenemende aantal persone met Alzheimer se demensie en die minimale gesondheidsorg befondsing vir die senior burgers in Suid-Afrika, is dit deel van die spraak- en taaltherapeute se rol om vir verpleging programme te motiveer en deel te neem aan die ontwerp daarvan. Verpleging programme wat ontwerp is deur spraak- en taaltherapeute sal fokus op kognitiewe (pasiënte se manier van dink en onthou) en kommunikatiewe (pasiënte se manier van praat en verstaan) stimulasie vir persone met geringe Alzheimer se demensie. Literatuur dui daarop dat verpleging programme met 'n direkte of indirekte fokus op kommunikatiewe en kognitiewe stimulasie al internasionaal toegepas is. Ongelukkig kan hierdie verpleging programme nie sonder aanpassing toegepas word in 'n land so kultureel uiteenlopend soos Suid-Afrika nie. Om verpleging programme te ontwikkel wat gemik is op verpleegsters in die Tygerberg distrik (Kaapstad, Wes-Kaap), is dit nodig om eers uit te vind wat die persepsies van die verpleegpersoneel is, met betrekking tot die kennis en kommunikasie van persone met 'n geringe Alzheimer se demensie. Hierdie Suid-Afrikaanse studie beoog dus om die persepsies van 'n groep verpleegsters te bepaal met betrekking tot die behandeling van Alzheimer se demensie, met spesifieke verwysing na die kommunikasie en kognitiewe vermoëns van hierdie pasiënte.

Al die bogenoemde inligting sal ingesamel word deur middel van 'n onderhoud. Sewe staat tehuise vir bejaardes in die Tygerberg distrik sal genooi word om aan die studie deel te neem. Die spesifieke verpleegsters wie in elke ouetehuis met Alzheimer se demensie pasiënte werk sal genooi word vir 'n onderhoud met die navorser. Die onderhoud sal by die tehuise vir bejaardes plaasvind. Die inligting met betrekking tot die deelnemers sal anoniem bly.

Waarom is u ouetehuis genooi om deel te neem?

Hierdie navorsing fokus op staat tehuise vir bejaardes. U ouetehuis voltooi die kriteria van hierdie navorsingstudie en word dus genooi om deel te neem.

Wat is die studie prosedures? Wat sal die deelnemers gevra word om te doen?

- Indien die verpleegsters saamstem om deel te neem aan die studie, sal hulle versoek word om aan individuele onderhoude deel te neem. Hierdie onderhoude sal ongeveer 45 minute duur. Die onderhoude sal rondom die verpleegsters skedules gereël word, sodat die versorging van die ouetehuis inwoners nie beïnvloed word nie.
- Die tyd en plek van die onderhoud sal rondom die verpleegsters skedule en gemak gereël word. Die lokaal moet asseblief toepaslik wees om 'n onderhoud in te voer en moet voorsiening maak vir die navorser se klank-opnames (die navorser sal die nodige toerusting verskaf en die opnames hanteer).
- Die vraelys wat gebruik sal word in die onderhoude bevat verskeie vrae oor die verpleegsters ervarings tydens hulle werk in die ouetehuis. Die fokus sal meer spesifiek op die kommunikasie (die pasiënte se manier van praat en verstaan) en kennis (die pasiënte se manier van dink en onthou) van persone in aanvangfase van Alzheimer se demensie, wees.
- Die inhoud van die onderhoude sal vertroulik bly. Die verpleegsters name sal nie op enige rekords verskyn nie. Die verpleegsters onderhoude sal 'n nommer ontvang, slegs vir die

navorser se identifisering van hulle rekords. Die verpleegsters identiteite sal anoniem bly en sal nie gebruik word in enige publikasie van die studie se resultate nie.

- Met die verpleegsters toestemming, wil ons graag die onderhoud opneem. Dit word gebruik vir later transkribering teen doeleindes van analise. Die verpleegsters name sal nie op die transkripsie verskyn nie. Die navorser sal die ontleding van die onderhoude handhaaf.

Sal die deelnemers voordeel trek deur deel te neem aan hierdie navorsingsprojek?

Daar is geen direkte voordele vir die verpleegsters deur hulle deelname aan hierdie studie. Die inligting wat verkry word uit hierdie studie kan nuttig wees in die ontwerp van moontlike aanpassings aan die interprofessionele leerplek in tuis vir bejaardes. Hierdie aanpassings kan dalk opleiding van verpleegsters verbeter en sodoende tot voordeel wees vir die versorging van die pasiënte.

Is daar enige risiko's verbonde aan die deelname aan hierdie navorsingsprojek?

Daar is geen risiko's betrokke met deelname aan die studie nie, en die verpleegsters deelname is volkome vrywillig.

Kan die deelnemers hul deelname aan hierdie studie staak en wat is hul regte rondom staking?

Die verpleegsters hoef nie deel te neem aan hierdie studie as hulle nie wil nie. As die verpleegsters aanvanklik ingestem het om deel te neem, maar later van mening verander, is hulle enige tyd welkom om die studie verlaat. Daar is geen boetes of nagevolge van enige aard indien die verpleegsters besluit om nie verder deel te neem aan die studie nie.

Wie sal toegang hê tot die inhoud van die verpleegsters onderhoude?

- Hiermee belowe die navorser dat alle persoonlike inligting wat die verpleegsters verskaf as vertroulik hanteer sal word, of net bespreek sal word met hulle toestemming.
- Geen opnames sal vrygestel word aan enige mens of entiteit ander as die navorser van die Universiteit van Stellenbosch nie. Die opnames sal vernietig word binne 6 maande na die verpleegsters betrokkeheid by die studie. Totdat die opnames vernietig word, word hulle gestoor in 'n rekenaar lêer beskerm deur 'n wagwoord waartoe slegs die navorser toegang het.
- Die anonieme wetenskaplike data wat geen persoonlike of identifiseerbare inligting bevat nie, kan aangebied word op vergaderings en gepubliseer word sodat die inligting nuttig vir ander kan wees.
- Ingesamelde data sal op rekenaar lêers gestoor word wat deur 'n wagwoord beskerm is waartoe slegs die navorser toegang het.

Sal die deelnemers betaal word vir hulle deelname aan die navorsingsprojek en is daar enige kostes verbonde aan hulle deelname?

Die verpleegsters sal nie betaal word vir deelname aan die navorsingsprojek nie en daar is geen kostes verbonde aan die deelname van die navorsingsprojek nie.

Is daar enigiets anders wat u moet weet of doen?

- U kan gerus vir Corinna Jeske kontak op 0723108949 indien u enige verdere vrae het of probleme van enige aard ondervind.
- U kan gerus die **Gesondheidsnavorsingsetiek administrasie** kontak op 021-938 9207 indien u enige bekommernisse of klagtes het wat nie bevredigend deur u navorser hanteer is nie.
- U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

Verklaring deur bestuurder

Met die ondertekening van hierdie dokument gee ek,, toestemming vir navorsing in (naam van ouetehuis).

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek die geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.

Geteken te (*plek*) op (*datum*) 2016.

.....
Handtekening van bestuurder

.....
Handtekening van getuie

Verklaring deur navorsers

Ek (*naam*) verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te (*plek*) op (*datum*) 2016.

.....
Handtekening van navorder

.....
Handtekening van getuie

Appendix 3 (c): English Informed Consent for the Participants

TITLE OF THE RESEARCH PROJECT:

The perceptions of nurses regarding the communication and cognition of persons with mild Alzheimer's dementia, within the Tygerberg district of Cape Town

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: *Corinna Jeske*

ADDRESS: *Division of Speech, Language and Hearing Therapy, Faculty of Medicine and Health Science, Stellenbosch University, Tygerberg*

CONTACT NUMBER: *0723108949*

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the student any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

Literature shows that the number of Alzheimer's dementia patients is raising. In South Africa, there is up to date little financial support for Alzheimer's dementia from the government. Due to minimal financial support from the government, persons with Alzheimer's dementia are rarely seen by therapists. Therapists could help patients maintain many of their skills for longer periods of time. For example, speaking exercises could help patients to remain speaking for years instead of months.

Therefore, given the increasing number of persons with Alzheimer's dementia and the minimal health care funding for the senior citizens in South Africa, the speech-, and language therapist's role includes motivating for and participating in the design of nursing programmes. Nursing programmes designed by speech-, and language therapists would be focused on cognitive (the way patients think and remember) and communicative (the way patients speak and understand) stimulation for persons with mild Alzheimer's dementia. Literature indicates that nursing interventions have been applied internationally, with direct or indirect focus on communicative

and cognitive stimulation. However, these interventions might not be applicable in a country as culturally diverse as South Africa. In order to design training interventions aimed at nurses working in the Tygerberg district (Cape Town, Western Cape), it would first be necessary to find out what the perceptions of the nursing staff is with regards to the cognition and communication of persons with mild Alzheimer's dementia. This South African study thus aims to determine the perceptions of a group of nurses regarding the treatment of Alzheimer's dementia, with specific reference to the communication and cognitive abilities of these patients.

The above-mentioned aim will be achieved through the use of interviews. 7 governmental old-age homes, within the Tygerberg district (Cape Town), will be asked to participate in the study. All home nurses, who have worked with Alzheimer's dementia patients and are willing to participate in the study, will be interviewed in each of the corresponding homes. The information provided by the nurses will remain anonymous.

Why have you been invited to participate?

You have been invited to take part in this study, as you are a nurse, working with Alzheimer's dementia in a governmental old-age home. Senior citizens, living in old-age homes, are likely to spend a great amount of time with you, the nursing staff. The nursing staff in these homes have the ability to provide intervention to persons with mild Alzheimer's dementia in terms of their communication (the way they speak and understand) and cognition (the way they think and remember). It is of importance to the researcher, to ask you about your perceptions of Alzheimer's dementia, specific to patients' communication and cognition.

What are the study procedures? What will I be asked to do?

- If you agree to take part in the study, it will involve your participation in an individual interview. Approximately 45 minutes will be needed to complete the interview. The interviews will be scheduled so that it does not affect the care of the elderly home residents.
- The time and venue of the interview will be arranged at your convenience. The venue has to allow for the interview to be appropriately conducted and for the audio-recording thereof.
- The questionnaire used in the interview contains several questions about your experiences during your work at the old-age home. More specifically, the questions will focus on the communication (the way patients speak and understand) and cognition (the way patients think and remember) of persons with early stage Alzheimer's dementia.
- The content of your interview will be confidential. Your name will not appear on any record. You will receive a number to identify your interview. Your identity will remain anonymous and will not be used in any publication of the study results.
- With your permission, we would like to audio-record the interview. It will later be transcribed for the purposes of analysis. Your name will not appear on the transcription. The researcher will do the analysis of the interviews.

Will you benefit from taking part in this research?

The information that is obtained in this study may be useful in making possible adjustments to the interprofessional learning opportunities arranged at the old-age homes to enhance the

training of nurses and thereby benefit the care of the patients. There are no direct benefits to you for participating in this study.

Are there in risks involved in your taking part in this research?

There are no risks involved in taking part in this research and participation is completely voluntary.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

Who will have access to your information provided during the interview?

- You are hereby promised that all personal information you give will remain confidential, or will be disclosed only with your permission.
- All recordings will not be released to any persons or entities other than the researcher of Stellenbosch University. The recordings will be destroyed within 6 months of completion of your involvement in the study. Until they are destroyed they will be stored in a password protected computer file to which only the researcher has access.
- The anonymous scientific data in which no individuals will be named or identified, resulting from the study, may be presented at meetings and published so that the information can be useful to others.
- Collected data will be stored on computer files that will be protected by a password known only to the researcher.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study and there will be no costs involved, if you do decide to take part.

Is there anything else that you should know or do?

- You can contact Corinna Jeske at 072-310-8949, if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- If requested, you can receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled “*The perceptions of nurses regarding the communication and cognition of persons with mild Alzheimer’s dementia, within the Tygerberg district of Cape Town*”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2016.

.....
Signature of participant

.....
Signature of witness

Informed consent for the audio-recording of the interview

The purpose of the audio-recording of this interview and the use, storage and final destruction of the tapes has been explained to me and I understand the explanation. I have been offered to answer any of my questions concerning the procedures involved in the recording of the interview and I have been given a copy of this form to keep.

.....
Participant Name (printed)

.....
Date of Birth

.....
Signature of Participant

.....
Date

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) on (*date*) 2016.

.....
Signature of investigator

.....
Signature of witness

Appendix 3 (d): Afrikaans Informed Consent for the Participants

TITEL VAN DIE NAVORSINGSPROJEK:

Die persepsies van verpleegsters oor die kommunikasie en kognisie van persone met geringe Alzheimer se demensie, in die Tygerberg distrik in Kaapstad

VERWYSINGSNOMMER:

HOOFNAVORSER: *Corinna Jeske*

ADRES: *Spraak-, Taal- & Gehoortherapie Afdeling, Fakulteit Geneeskunde en Gesondheidswetenskappe, Universiteit van Stellenbosch, Tygerberg.*

KONTAKNOMMER: 0723108949

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorser daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook enige tyd aan die navorsingsprojek onttrek, selfs al het u aanvanklik ingestem om deel te neem.

Hierdie navorsingsprojek is deur die **Gesondheidsnavorsing Etiekkomitee (GNEK) van die Universiteit Stellenbosch** goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

Literatuur wys daarop dat die aantal Alzheimer se demensie pasiënte besig is om toe te neem. Wat die versorging van Alzheimer se demensie pasiënte betref, word daar tot nou toe net minimale finansiële ondersteuning deur die Suid Afrikaanse regering aangebied. Beperkte finansies beteken dat Alzheimer se demensie pasiënte nie gereeld genoeg terapie kan ontvang nie. Terapie kan vir die pasiënte help om vaardighede vir langer periodes te behou. By voorbeeld, deur spraak oefeninge te implementeer, kan 'n pasiënt se verlies aan spraakvermoë vertraag word na jare inplaas van maande. Dit sou dus voordelig wees om verpleegsters op te lei om die terapeutiese vaardighede aan te leer, sodat hulle die terapie met die pasiënte kan beoefen en sodoende die Alzheimer se demensie pasiënte help met hulle kommunikasie- (manier van praat en verstaan) en kognitiewe (manier van dink en onthou) vaardighede. Om 'n suksesvolle intervensieprogram te ontwerp, beoog hierdie studie om die persepsies van verpleegsters in verband met die behandeling van Alzheimer se demensie vas te stel, met spesifieke verwysing na die kommunikasie en kognitiewe vermoëns van hierdie pasiënte.

Gegewe die toenemende aantal persone met Alzheimer se demensie en die minimale gesondheidsorg befondsing vir die senior burgers in Suid-Afrika, is dit deel van die spraak- en taaltherapeute se rol om vir verpleging programme te motiveer en deel te neem aan die ontwerp daarvan. Verpleging programme wat ontwerp is deur spraak- en taaltherapeute sal fokus op kognitiewe (pasiënte se manier van dink en onthou) en kommunikatiewe (pasiënte se manier van praat en verstaan) stimulasie vir persone met geringe Alzheimer se demensie. Literatuur dui daarop dat verpleging programme met 'n direkte of indirekte fokus op kommunikatiewe en kognitiewe stimulasie al internasionaal toegepas is. Ongelukkig kan hierdie verpleging programme nie sonder aanpassing toegepas word in 'n land so kultureel uiteenlopend soos Suid-Afrika nie. Om verpleging programme te ontwikkel wat gemik is op verpleegsters in die Tygerberg distrik (Kaapstad, Wes-Kaap), is dit nodig om eers uit te vind wat die persepsies van die verpleegpersoneel is, met betrekking tot die kennis en kommunikasie van persone met 'n geringe Alzheimer se demensie. Hierdie Suid-Afrikaanse studie beoog dus om die persepsies van 'n groep verpleegsters te bepaal met betrekking tot die behandeling van Alzheimer se demensie, met spesifieke verwysing na die kommunikasie en kognitiewe vermoëns van hierdie pasiënte.

Al die bogenoemde inligting sal ingesamel word deur middel van 'n onderhoud. Sewe staat tehuise vir bejaardes in die Tygerberg distrik sal genooi word om aan die studie deel te neem. Die spesifieke verpleegsters wie in elke ouetehuis met Alzheimer se demensie pasiënte werk sal genooi word vir 'n onderhoud met die navorser . Die onderhoud sal by die tehuise vir bejaardes plaasvind. Die inligting met betrekking tot die deelnemers sal anoniem bly.

Waarom is u genooi om deel te neem?

U is genooi om deel te neem aan hierdie studie omdat u 'n verpleegster in 'n staat ouetehuis is, en u vir die versorging van Alzheimer se demensie pasiënt verantwoordelik is. Senior burgers, wat in tehuise vir bejaardes bly, spandeer waarskynlik 'n groot hoeveel tyd saam met u en die res van die verpleegpersoneel. Die verpleegpersoneel in hierdie huise het die vermoë om persone met geringe Alzheimer se demensie te help in terme van hul kommunikasie (die manier waarop hulle praat en verstaan) en kennis (die manier waarop hulle dink en onthou). Dit is van belang vir die navorser om u persepsies van Alzheimer se demensie te bepaal.

Wat is die studie prosedures? Wat sal u gevra word om te doen?

- Indien u saamstem om deel te neem aan die studie, sal u versoek word om aan 'n individuele onderhoud deel te neem. Hierdie onderhoud sal ongeveer 45 minute duur. Die onderhoud sal rondom u skedules gereël word, sodat die versorging van die ouetehuis inwoners nie beïnvloed word nie.
- Die tyd en plek van die onderhoud sal rondom u skedule en gemak gereël word. Die lokaal moet asseblief toepaslik wees om 'n onderhoud in te voer en moet voorsiening maak vir die navorser se klank-opnames (die navorser sal die nodige toerusting verskaf en die opnames hanteer)..
- Die vraelys wat gebruik sal word in die onderhoud bevat verskeie vrae oor u ervarings tydens u werk in die ouetehuis. Die fokus sal meer spesifiek op die kommunikasie (die

pasiënte se manier van praat en verstaan) en kennis (die pasiënte se manier van dink en onthou) van persone in aanvangfase van Alzheimer se demensie, wees.

- Die inhoud van die onderhoud sal vertroulik bly. U naam sal nie op enige rekords verskyn nie. U onderhoud sal 'n nommer ontvang, slegs vir die navorser se identifisering van u rekord. U identiteit sal anoniem bly en sal nie gebruik word in enige publikasie van die studie se resultate nie.
- Met u toestemming, wil ons graag die onderhoud opneem. Dit word gebruik vir later transkribering teen doeleindes van analise. U naam sal nie op die transkripsie verskyn nie. Die navorser sal die ontleding van die onderhoude handhaaf.

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

Daar is geen direkte voordele vir u deur u deelname aan hierdie studie. Die inligting wat verkry word uit hierdie studie kan nuttig wees in die ontwerp van moontlike aanpassings aan die interprofessionele leergeleenthede in tehuise vir bejaardes. Hierdie aanpassings kan dalk opleiding van verpleegsters verbeter en sodoende tot voordeel wees vir die versorging van die pasiënte.

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

Daar is geen risiko's betrokke met deelname aan die studie nie, en u deelname is volkome vrywillig.

Kan u deelname aan hierdie studie staak en wat is u regte rondom staking?

U hoef nie deel te neem aan hierdie studie as u nie wil nie. As u aanvanklik ingestem het om deel te neem, maar later van mening verander, is u enige tyd welkom om die studie verlaat. Daar is geen boetes of nagevolge van enige aard indien u besluit om nie verder deel te neem aan die studie nie.

Wie sal toegang hê tot die inhoud van u onderhoud?

- Hiermee belowe die navorser dat alle persoonlike inligting wat u verskaf as vertroulik hanteer sal word, of net bespreek sal word met u toestemming.
- Geen opnames sal vrygestel word aan enige mens of entiteit ander as die navorser van die Universiteit van Stellenbosch nie. Die opnames sal vernietig word binne 6 maande na u betrokkenheid by die studie. Totdat die opnames vernietig word, word hulle gestoor in 'n rekenaar lêer beskerm deur 'n wagwoord waartoe slegs die navorser toegang het.
- Die anonieme wetenskaplike data wat geen persoonlike of identifiseerbare inligting bevat nie, kan aangebied word op vergaderings en gepubliseer word sodat die inligting nuttig vir ander kan wees.
- Ingesamelde data sal op rekenaar lêers gestoor word wat deur 'n wagwoord beskerm is waartoe slegs die navorser toegang het.

Sal u betaal word vir u deelname aan die navorsingsprojek en is daar enige kostes verbonde aan u deelname?

U sal nie betaal word vir deelname aan die navorsingsprojek nie en daar is geen kostes verbonde aan die deelname van die navorsingsprojek nie.

Is daar enigiets anders wat u moet weet of doen?

- U kan gerus vir Corinna Jeske kontak op 0723108949 indien u enige verdere vrae het of probleme van enige aard ondervind.
- U kan gerus die **Gesondheidsnavorsingsetiek administrasie** kontak op 021-938 9207 indien u enige bekommernisse of klagtes het wat nie bevredigend deur u navorser hanteer is nie.
- U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,, om deel te neem aan die navorsingsprojek getiteld “Die persepsies van verpleegsters oor die kommunikasie en kennis van persone met geringe Alzheimer se demensie, in die Tygerberg distrik in Kaapstad”.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het, en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek enigtyd van die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (*plek*) op (*datum*) 2016.

.....
Handtekening van deelnemer

.....
Handtekening van getuie

Ingeligte toestemming vir klank-opnames van die onderhoud

Die doel van die klank-opname van die onderhoud en die gebruik, stoor en finale vernietiging van die opnames is aan my verduidelik en ek verstaan die verduideliking. Daar is 'n geleentheid geskep vir my om enige vrae rondom die prosedures rakend klank-opnames te vra. Ek verklaar ook dat 'n kopie van hierdie vorm aan my beskikbaar gestel is vir my eie rekords.

.....
Naam van deelnemer (gedruk)

.....
Geboortedatum

.....
Handtekening van Deelnemer

.....
Datum

Verklaring deur navorser

Ek (*naam*) verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te (*plek*) op (*datum*) 2016.

.....
Handtekening van navorser

.....
Handtekening van getuie

Appendix 4 (a): English Cognitive and Communicative Stimulation Programme

2 Cognition:

What is the problem?

How can we help?

They become more and more forgetful.

Use objects, photos or calendars to help them remember (e.g. When somebody visits them, ask them to put their name down or draw a smiley onto the calendar. That way they know somebody visited them and nurses cannot be accused of lying about visitors, who in their opinion never came to visit because they forgot about their visitors).

Always put their things in the same spot so that you cannot be accused of stealing their things.

Exercise their brain by singing songs or playing games with them (that way they have to think and remember the song or games you are playing and they speak to you whilst having fun).

They often speak about the past, remember the past better and speak about the past as if it was happening right now.

Allow them to create their own world and ask more questions about it (e.g. "That is interesting! What happened next, Mama?").

If you want to correct their stories do it in a sensitive manner by showing pictures or photos and asking questions about it (e.g. "Mama, who is this? What happened here?" By asking these questions and showing pictures, they might rectify their story themselves).

Allow them to speak about the past. Show them photos or objects to help them remember (speaking about the past might help them to overcome past problems and is a way for you to connect with them).

Always show interest in their stories even if you heard them before (and try and ask more questions about their stories).

They have problems thinking and reasoning about why something happened or what to do next. They also struggle to solve problems.

Exercise their brains by asking questions about their past or how they would solve a problem. Provide them with pictures if they struggle to answer the questions. (E.g. You ask them what they would do if they were in a shop and realized they forgot their purse. If they struggle to answer, you can show them a phone or a photo of the old-age home. This might help them to think about their options or ways to solve the problem. They might realise that they could call somebody to bring their purse or they could walk back to the home and then return to the shop).

Exercise their brains by playing games (this is a fun way to make them think).

They often forget the date and become lost in places.

They remember certain signs and pictures. Try to not change the environment or their routine otherwise they might become confused or lost.

Use a calendar for them to remember the date (e.g. You can make it a routine that every morning you help them cross out the day that has passed. This way they will know what day it is).

Contact

Ms. Corinna Jeske
Speech-Language Therapist
cjeske@gmail.com



TIPS FOR MILD ALZHEIMER'S DEMENTIA

Let us stand together and give mom, dad, granny or granddad the help and support they need and deserve.



Improving communication and cognition of persons with mild Alzheimer's dementia

Alzheimer's dementia is:

- if people are becoming very forgetful
- if their thinking abilities are worsening
- if they are losing the ability to have a conversation
- their inability to do daily activities like bathing and dressing, during later stages of Alzheimer's dementia
- Alzheimer's dementia becomes worse as time passes



1. Communication is:

- to say or share what you want, need or think about
- to give or share information about facts, events, experiences, feelings and yourself
- to understand what the other people are saying
- to speak about and respond to what the others said
- to connect and speak with people around you
- to build a relationship with the people around you

2. Cognition is:

- to know where and who you are and what time it is
- to decide on what you want or need
- to have or create an opinion
- to come up with an idea
- to think or reason about why something is happening
- to think about how you can solve a problem
- to remember a past event or experience

1

Communication:

What is the problem?

How can we help?



They always change the topic (e.g. you speak about the church and they start speaking about their childhood).



Choose a topic they want to speak about (e.g. their childhood).



Use photos or objects to show them what you are talking about.



Ask questions related to the photo or object (e.g. "Mama, what did you do here?").



Use short and easy sentences to help them understand what you are saying (e.g. "Let's eat Mama" instead of "I think we should go and eat Mama").



Pretend to know the topic they speak about and ask more questions about the topic.



Take their side if they complain about something (even if you know what they are saying is wrong, but if you disagree you might start a fight and upset them).



Try and agree with what they say or correct them very sensitively (e.g. "That's very interesting, Mama. But wasn't it like this?").



Show interest in what they are saying (e.g. "That's very interesting, Mama!").



They sometimes don't want to speak to you.



Motivate them to speak to you (e.g. show them a photo they love and say "Mama, what happened here?").



Motivate them to decide on what they need or want ("Mama, do you want to eat?").



Always allow them to finish their story and don't interrupt them or speak on their behalf ("Mama, what happened next?").



Be aware of non-verbal cues (e.g. hand-movements or facial expressions).



They sometimes struggle to understand you.



They sometimes struggle to understand you.



Show them an object or photo to help them understand.



Repeat what you said (but don't say that you have said that already).



Provide them with small bits of information at a time (only one idea), so that they can understand (e.g. "Mama, I was in town. I saw these shoes. I bought them for you."). Check if they understood.



Don't speak too fast. Use a normal speaking pace.



Speak calmly and gently so that they want to listen to and understand you (if you speak angrily, loudly or as if you are stressed or in a hurry, they might not want to listen to you).



They sometimes don't pay attention or focus on what you say or do.



Put their chair in front of you so that they have to look at you (always look at them, when speaking to them).



Get their attention before speaking. Continue making eye-contact.



Try and get rid of all things that might distract them (e.g. switch off the TV or radio, move their chair away from the window or door).



Put their chair close to you.



Appendix 4 (b): Afrikaans Cognitive and Communicative Stimulation Programme

2 Kognisie:

Wat is die probleem?

9 Hoe kan ons help?

Hulle raak meer en meer vergeetagtig.

Gebruik voorwerpe, foto's of kalenders om hulle te help onthou (bv. Wanneer iemand by hulle kom kuier, vra hulle om op die kalender hulle naam neer te skryf of 'n smiley te teken. Op die manier weet hulle iemand het hulle besoek en verpleegsters kan nie beskuldig word dat hulle lieg oor besoekers, wat in hulle opinie nooit gekom kuier het maar hulle het net vergeet van hulle besoekers).

Sit hulle dinge altyd in die dieselfde plek, sodat jy nie kan beskuldig word van diefstal nie.

Oefen hulle brein deur liedjies te sing of spelletjies te speel saam hulle (hierdie is 'n manier vir hulle om te dink en te onthou hoe die lied of spelletjies werk en tseftertyd praat hulle met jou tenwyl hulle pret het).

Hulle praat dikwels oor die verlede, onthou die afgelope beter en praat oor die verlede asof dit nou gebeur.

Laat toe dat hulle hulle eie wêreld skep en vra meer vrae daaroor (bv. "Dit is interessant! Wat gebeur volgende, Mamma?").

As jy hulle stories wil regstel doen dit op 'n sensitiewe manier deur prente of foto's te wys en vra daaroor te vra (bv. "Mamma, wie is die persoon? Wat het hier gebeur?"). Deur middel van hierdie vrae en foto's kan hulle dalk self hulle storie regstel.

Laat hulle oor die verlede praat. Wys hulle foto's of voorwerpe om hulle te help onthou (om oor die verlede te praat kan hulle help om probleme uit die verlede te oorkom en dit is 'n manier vir jou om 'n verhouding te bou met hulle).

Stel altyd belang in hulle verhaale selfs as jy hulle al voorheen gehoor het (en probeer om meer vrae te vra oor hulle stories).

Onthou: Hulle vergeet nie aspris nie. Hulle herhaal nie hulle storie aspris nie.

Hulle sukkel om te dink en redeneer oor hoekom iets gebeur het of wat om volgende te doen. Hulle sukkel ook om probleme op te los.

9 Oefen hulle brein deur vrae te vra oor hulle verlede of hoe hulle 'n probleem sou oplos. Gee vir hulle foto's as hulle sukkel om die vrae te beantwoord. (bv. Jy vra hulle wat hulle sou doen as hulle in 'n winkel is en besef hulle het hulle beursie vergeet. As hulle sukkel om te antwoord, kan jy vir hulle 'n selfoon of 'n foto van die ouetehuis wys. Dit kan hulle help om te dink oor hulle opsies of maniere om die probleem op te los. Hulle besef dalk dat hulle iemand kan bel om hulle beursie te bring of hulle kan terug loop na die ouetehuis toe en dan weer winkel toe).


9 Oefen hulle brein deur spelletjies te speel (dit is 'n prettige manier om hulle te laat dink).

Hulle vergeet dikwels die datum en raak verlore in plekke.

9 Hulle onthou sekere tekens en prentjies. Probeer die omgewing en hulle roetine nie verander nie andersins kan hulle deurekkaar of verlore raak. Gebruik 'n kalender vir hulle om die datum te onthou (bv. Jy kan dit 'n roetine maak dat jy elke oggend hulle help om die dag wat verby is uit te krap. Op hierdie manier sal hulle weet watter dag dit is).

WENKE VIR ALZHEIMER'S DEMENSIE

Laat ons saamstaan en ma, pa, ouma of oupa die hulp en ondersteuning gee wat hulle nodig het en verdien.



Kontak

Mej. Corinna Jeske
Sprake-Taalterapeut
cjeske@gmail.com

Die verbetering van kommunikasie en kognisie van persone met geringe Alzheimer se demensie

Alzheimer se demensie is:

- as mense baie vergeetagtig raak
- as hulle dinkvaardighede verslegter
- hulle onvermoë om daaglikse aktiwiteite soos bad en aantrek uittevoer tydens die latere stadium van Alzheimer's demensie
- Alzheimer's demensie word erger met die verloop van tyd



1. Kommunikasie is:

- om te sê of te deel wat jy wil hê, benodig of dink
- om inligting oor feite, gebeurtenisse, ervarings, gevoelens en jouself te deel
- om te verstaan wat die ander mense sê
- om te praat oor en te reageer op wat die anders sê
- om in verbinding te bly en te praat met mense rondom jou
- om 'n verhouding te bou met die mense rondom jou

2. Kognisie is:

- om te weet waar en wie jy is en wat tyd dit is
- om te besluit wat jy wil hê of nodig
- om 'n mening te hê of te skep
- om met 'n idee te skep
- om 'n gebeurtenis of ondervinding van die verlede te onthou
- om daaroor te dink of redeneer hoekom iets gebeur
- om te dink oor hoe jy 'n probleem kan oplos



Kommunikasie:

Wat is die probleem?

Hoe kan ons help?



Hulle verander altyd die onderwerp (bv. jy praat oor die kerk en hulle begin praat oor hulle kindertjies).



Kies 'n onderwerp waarom hulle wil praat (bv. hulle kindertjies).



Gebruik foto's of voorwerpe om hulle te wys waarom jy praat.



Vra vroeë wat verband hou met die foto of voorwerp (bv. "Mamma, wat het jy hier doen?").



Gebruik kort en maklike sinne om hulle te help verstaan wat jy sê (bv. "Kom ons eet, Mamma" in plaas van "Ek dink ons moet gaan eet, Mamma").



Gee voor die onderwerp te ken waarom hulle praat en vra meer vroeë oor die onderwerp.



Neem hulle kant as hulle oor iets kla (selfs as jy weet wat hulle sê is verkeerd, maar as jy nie saamstem nie kan jy 'n geveg begin of hulle onstel).



Probeer en stem saam met wat hulle sê of stel hulle reg in 'n baie sensitiewe manier (bv. "Dit is baie interessant, Mamma. Maar was dit nie so?")



Stel belang in wat hulle sê (bv. "Dit is baie interessant, Mamma!").



Hulle soms wil nie met jou praat nie.



Motiveer hulle om met jou te praat (bv. wys hulle 'n foto waarvan hulle hou en sê: "Mamma, wat hier gebeur?").



Motiveer hulle om te besluit oor wat hulle nodig het of wil hê ("Mamma, wil jy eet?").



Gee hulle altyd die kans om hulle storie klaar te vertel en moet hulle nie onderbreek of praat namens hulle nie ("Mamma, wat het volgende gebeur?").



Wees bewus van nie-verbale aanwysings (bv. hand-bewegings of gesigsuitdrukings).



Hulle sukkel soms om jou te verstaan.



Wys hulle 'n voorwerp of 'n foto om hulle te help verstaan.



Herhaal wat jy gesê het (maar nie sê dat jy dit alreeds gesê het).



Voor sien hulle met min inligting (een gedagte), sodat hulle kan verstaan (bv. "Mamma, ek was in die stad. Ek het hierdie skone gesien. Ek het hulle vir jou gekoop."). Kyk of hulle verstaan het.



Moenie te vinnig praat. Gebruik 'n normale spraaktempo.



Prat rustig en versigtig sodat hulle wil luister en verstaan wat jy sê (as jy woedend, hard of hastig praat of asof jy gespanne is, kan dit wees dat hulle nie na jou wil luister nie).



Soms fokus en gee hulle geen aandag op wat jy sê of doen nie.



Sit hulle stoel voor jou, sodat hulle na jou toe moet kyk (kyk altyd na hulle as jy met hulle praat).



Hulle sukkel soms om jou te verstaan.



Wys hulle 'n voorwerp of 'n foto om hulle te help verstaan.



Herhaal wat jy gesê het (maar nie sê dat jy dit alreeds gesê het).



Voor sien hulle met min inligting (een gedagte), sodat hulle kan verstaan (bv. "Mamma, ek was in die stad. Ek het hierdie skone gesien. Ek het hulle vir jou gekoop."). Kyk of hulle verstaan het.



Moenie te vinnig praat. Gebruik 'n normale spraaktempo.



Prat rustig en versigtig sodat hulle wil luister en verstaan wat jy sê (as jy woedend, hard of hastig praat of asof jy gespanne is, kan dit wees dat hulle nie na jou wil luister nie).



Soms fokus en gee hulle geen aandag op wat jy sê of doen nie.



Sit hulle stoel voor jou, sodat hulle na jou toe moet kyk (kyk altyd na hulle as jy met hulle praat).



Kry hulle aandag voordat jy praat. Hou altyd oogkontak.



Probeer om ontslae te raak van al die dinge wat dalk hulle aandag kan trek (bv. Skakel die televisie of radio af, beweeg hulle stoel weg van die verster of deur).



Sit hulle stoel naby aan joune.



Appendix 5: Approval Letter by the Health Research Ethics Committee at Stellenbosch University



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jou kennisvennoot • your knowledge partner

Approval Notice

Response to Modifications- (New Application)

31-May-2016

Jeske, Corinna C

Ethics Reference #: S16/04/076

The perceptions of nurses regarding the communication and cognition of persons with mild Alzheimer's dementia, Title: within the Tygerberg district in the Cape Town area

Dear Miss Corinna Jeske,

The **Response to Modifications - (New Application)** received on **11-May-2016**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **31-May-2016** and was approved.

Please note the following information about your approved research protocol: Protocol Approval Period: **31-May-2016 -30-May-2017**

Please remember to use your **protocol number** (**S16/04/076**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States

Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City

Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 219389819.

Included Documents:

Protocol

General Checklist

Informed consent - English - Manager

20160531 HREC modifications letter

Budget

Interview-English

Declaration C Jeske

CV C Jeske

20160531 MOD Informed consent - English Manager

Biographical questionnaire English

CV B Gerber

20160531 MOD Informed Consent - Afrikaans Manager

Declaration B Gerber Protocol Synopsis

CV F Bardien

Interview - Afrikaans

Application form

20160531 MOD Informed consent English Participants

Informed Consent - Afrikaans- Participants

Biographical questionnaire Afrikaans

20160531 Informed Consent - Afrikaans Participants

Declaration F Bardien

Informed consent - English - Participants

Informed Consent - Afrikaans - Manager

20160531 MOD Cover letter researcher

Sincerely,

Ashleen Fortuin

HREC Coordinator

Health Research Ethics Committee 2

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.

2.Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.

4.Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur**. If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5)**

days of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HRECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating Procedures www.sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC

8.Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.

9.Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.

10. Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.

11. On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

Appendix 6: The Researcher's Reflection

During my undergraduate studies, we occasionally worked in governmental old-age homes. I came in contact with a few persons with Alzheimer's dementia and I started wondering how we could assist these patients. Most patients that I saw were using echolalia or presented as mute already (late stage of Alzheimer's dementia). I spoke to nurses and they said that the patients' verbal abilities regressed 'very quickly'. According to them, patients' speedy regression was part of the course of Alzheimer's dementia and nurses seemed to believe that 'there was nothing they can do about it'. Overall, the nurses seemed very helpless with regards to the persons with Alzheimer's dementia.

Following these experiences in the old-age home, my idea for my master research evolved. I started informing myself about cognitive and communicative stimulation programmes for persons with Alzheimer's dementia. After identifying that stimulation assists persons with mild Alzheimer's dementia in maintaining cognitive and communicative functions for longer periods of times, I realised that most persons with Alzheimer's dementia, living in governmental old-age homes, might not have the funds to be seen by a speech-, and language therapist (SLT). This lead me to research nurses' roles in old-age homes.

I realised that nurses were spending the majority of time with these patients and were thus well positioned to provide cognitive as well as communicative stimulation and based on my interactions with nurses working with persons with Alzheimer's dementia, I believed that they would desire to assist persons with Alzheimer's dementia more than they currently did. In order to identify the perceptions of nurses regarding the communication and cognition of persons with Alzheimer's dementia, I decided to conduct this study in governmental old-age homes within the Tygerberg district. I believe that it is essential to take nurses' perceptions into account, prior to generating and enrolling nurses in cognitive and communicative stimulation training programmes.

I am thus hoping that my research is merely a stepping stone to assist the generation of stimulation programmes tailored according to nurses' needs within the Tygerberg district. This might help nurses to provide improved care for persons with mild Alzheimer's dementia in terms of their cognition and communication and additionally aims at reducing nurses' feelings of helplessness involving this condition (as reported above). Moreover, it will benefit persons with mild Alzheimer's dementia and their families, as cognitive and communicative functions could be maintained for longer periods of time.